

CADTH Reimbursement Review Patient Input Template

Name of Drug: Verzenio (abemaciclib)

Indication: HR-positive, HER2-negative advanced or metastatic breast cancer in combination with an aromatase inhibitor in postmenopausal women, OR in combination with fulvestrant in women with disease progression following endocrine therapy, OR as a single agent in women with disease progression following endocrine therapy and at least 2 prior chemotherapy regimens.

Name of Patient Group: Rethink Breast Cancer

Author of Submission: Jenn Gordon

1. About Your Patient Group

Rethink Breast Cancer (Rethink) is a Canadian charity known for making positive change. Rethink educates, empowers and advocates for system changes to improve the experience and outcomes of those with breast cancer, focusing on historically underserved groups: people diagnosed at a younger age, those with metastatic breast cancer and people systemically marginalized due to race, income or other factors. We foster spaces to connect, listen, empower and rethink breast cancer, together. Rethink's strategic priorities and organizational direction are guided by the unique, unmet needs identified by breast cancer patients and their families.

Programs and Activities

- Rethink Breast Cancer builds community, bringing patients with various stages of breast cancer together through our private and public social spaces as well as in-person events
- Rethink runs patient retreats and facilitates peer-support
- Rethink creates and runs education forums and conferences
- Rethink creates support and education tools, resources and content
- Rethink funds and supports breast cancer research

You can find out more by visiting:

[Rethink Breast Cancer Instagram](#)

[Rethink Breast Cancer Website](#)

2. Information Gathering

For over 20 years, Rethink has been working closely with breast cancer patients in Canada. We learn from and listen to the community to understand their values, priorities and pain points to help drive change and system improvements. Each year, we learn from the patients we serve, survey and collaborate with. We learn from the 24 individuals that we work extremely closely with as key patient advisors; the hundreds of patients that have shared their stories on our blog; the 700 patients that participate in our virtual support groups each year; the 2,100 members of our private peer-support network; and the 44,000 people that have joined our Instagram community. We listen, learn, engage and have conversations in all these spaces.

Rethink also benefits from regular knowledge exchange with our Scientific Advisory Committee, which includes some of the leading clinical scientists in Canada who treat breast cancer.

For this submission, we have drawn on our observations and insights gathered through programming and meetings with breast cancer patients as described above. We have also drawn on the results from an online survey with 78 patients living with metastatic breast cancer (MBC) conducted by Rethink Breast Cancer to document the lived experience of patients and caregivers. Patients completed the survey between September 2018 and April 2019.

In addition, we drew on insights from interviews conducted in January and February 2025 with four people who are living with metastatic breast cancer and who have experience taking abemaciclib to treat their disease.

3. Disease Experience

Most people in the Rethink community are diagnosed at a younger age. When young people get breast cancer it may be more aggressive, which can lead to tougher treatments. In addition, those diagnosed in their 20s, 30s and early 40s face age-specific issues such as fertility or family-planning challenges, diagnosis during pregnancy, childcare, impact on relationships, body image, dating and sexuality, feeling isolated from peers who don't have cancer, career hiatuses, and financial insecurity. The physical and emotional toll that a breast cancer diagnosis and treatment take on a young person's life is devastating and traumatic.

Fear of recurrence is a reality for our community and for good reason. Despite improvements made with early detection and treatment for early-stage breast cancer, there's approximately a 20-30% chance that early breast cancer will metastasize. Moreover, 5-10% of newly diagnosed breast cancers are metastatic. There is currently no cure for metastatic breast cancer and patients' goal with treatment is to live as well as they can for as long as they can. Patients with metastatic HR+/HER2- cancers survive 4 to 5 years on average.

Processing this reality of a life-limiting diagnosis is extremely difficult, especially for the young patients in our community and the emotional impacts on quality of life cannot be understated. The physical and psychosocial challenges of metastatic breast cancer negatively impact both the patients and their loved ones who are often their caregivers. Most people with metastatic breast cancer have widespread disease, with metastasis to bone being the most common. Lung, liver, lymph nodes and skin are also commonly involved; while metastasis to the brain is less common for hormone positive MBC patients, it can happen too. Symptoms of hormone positive MBC depend on the sites of the metastasis and include fatigue, shortness of breath for lung metastasis, pain, and bone fractures for bone metastasis as well as nausea, headache and of course challenges doing normal daily activity. The challenges and uncertainty of living with MBC affects both the patients and their loved ones who support and help care for them.

4. Experiences With Currently Available Treatments

For people with HR+/HER2-negative MBC CDK4/6 inhibitors have become standard of care for first line therapy. There are currently three drugs in this class; palbociclib, ribociclib and abemaciclib. Prior to CDK4/6 inhibitors, patients were prescribed aromatase inhibitors(AIs) or selective estrogen receptor downregulator's(SERDs) that were not as effective as managing this stage of breast cancer as a single agent compared with combining them with a CDK4/6 inhibitors.

While there are currently 2 other available CDK4/6 inhibitors for the treatment of HR-positive, HER2-negative metastatic breast cancer, there are some differences between the three drugs that are relevant for patients

when considering what course of treatment is right for them. The side effect profile of the three CDK4/6 inhibitors differ, as does the dosing schedule and the monitoring schedule. Patients may have co-morbidities that need to be considered when choosing the right treatment and having choice may help ensure that they are able to adhere to a treatment that will help manage their cancer and also provide them with a good quality of life. Recent data has also shown a benefit in overall survival for abemaciclib, and patients in Canada should have the opportunity this therapy if their oncologist advises that this is the best treatment for them.

Chemotherapy is also a treatment used for this type and stage of breast cancer; however, chemotherapies are given sequentially usually with diminishing responses with each line of chemotherapy. Although initial lines of chemotherapy may provide a few months of progression free survival, this decreases substantially with later lines.

Metastatic breast cancer patients in our community go to great lengths to avoid standard chemotherapy and they are hit hard both emotionally and physically when it does come to that. In our community, we see a rapid decline once patients progress to having only standard chemotherapies as remaining options.

"While your tumour is responding to endocrine therapy, you tend to be able to remain longer on the treatment and stable. Then when it starts to progress, and you need to go into chemo because you don't have anything else, it's just faster, you know, and things go down so quickly."

-Rosilene, MBC patient

Patients on standard chemo have a lot of difficulty managing their illnesses. Hospital appointments increase and they become mostly housebound managing side-effects of treatment.

"On weekly IV chemo, your normal life pretty much ends. It requires two visits per week for either blood work or for the chemo. The rest of the week is managing side effects of nausea, fatigue, pain, worsening neuropathy. And that's with me being in the cohort of people who 'tolerates well.'"

-Heather, MBC patient

"My year on chemotherapy was a full-time job dealing with suppressed neutrophil counts that caused countless treatment delays and quality of life compromising side effects. When I was offered the chance to rely entirely on a newer therapy, the results were game changing and allowed me to get back to my active and scheduled lifestyle as it once had been. Knowing that a cutting-edge treatment option like Trodelvy may be available to me when/if I need it outside of standard of care shelf-life chemotherapies, in the precious time to come, is what helps me stay present and positive as I navigate life with this incurable diagnosis. Everyone deserves a shot at what works best for them and the more therapies available to us are key. Stage 4 needs so much more."

-Jen, MBC patient, diagnosed de novo

"My biggest concern with fear of progression, is that my subtype changes from triple positive to any other subtype. So of course, the more treatments that are available that are effective and not chemo are important to me. I already did loads of chemo because my targeted therapy had to go on pause because of the damage to my heart. It was not fun knowing that I could be left on chemo if the cardiotoxicity didn't improve."

-Margaret, MBC patient, diagnosed de novo while pregnant

5. Improved Outcomes

Each individual patient brings their own personal values and goals to their discussions with their oncology team. Communication and trust in their team is essential. It's important that patients have a clear understanding of trade-offs and are well prepared for common side-effects of a given treatment.

When it comes to therapy for metastatic breast cancer, the primary improvement patients seek is to extend their life beyond what is expected with the current publicly, and to choose, along with their oncologist, the therapy that is best for them.

As Jessica, a hormone positive, MBC patient from our community explains, when the stakes are so high, even a few extra months of survival matter. She explains:

"...those months could be the difference that lets me see my son start kindergarten; they could be the ones that give me time to get him off diapers before it all falls on dad; Or they could be the first time he says I Love You. While a few months are short on time they are bursting with possibility. Life happens in moments after all. Every scan matters.

Only, it's not simply a matter of days, it's also a matter of quality days. It's hard to make memories suffering the side effects of chemo on the couch. It's impossible to keep up with a toddler while managing the debilitating fatigue. An additional line of treatment that allows me quality time with my family is welcomed with open grateful arms...It's not easy for anyone to estimate the value of an extra day of life, but in my case, it could also mean my two-year old has one more day with mom. I'll give him every day I can."

In Rethink's 2018-2019 MBC survey, patients rated controlling disease and extending life expectancy as the most important outcomes for treatment. This suggests that patients value long-term health outcomes over immediate concerns like reducing symptoms or managing side effects. See the full survey results, along with methodology in Appendix A. Comments from the MBC patients surveyed included:

- "Symptom management and shrinking the cancer is the most important thing. Living well is the next most important thing."
- "Keeping me alive for my kids"
- "I want to live, LIVE, and enjoy my life for many more years and not be so afraid."

6. Experience With Drug Under Review

Rethink interviewed 4 patients in 2025 as part of the re-submission who had experience taking abemaciclib for HR+ HER2-negative MBC.

Patient 1: Lisa

I was diagnosed with breast cancer in 2019, I had been undergoing regular mammograms, but found the lump myself. At first it was thought that it was confined to the breast so I started chemo, but was also experiencing back pain scans were done to try to identify what was causing the pain. Bone metastasis were discovered in my scans, so my diagnosis was changed to DeNovo metastatic breast cancer.

In January 2020 I started taking Verzenio and letrozole, which I am still on. Because I have bone metastasis, they will never completely disappear, but they are well managed, not growing, and my scans continue to come back as unremarkable, with no signs of progression. There is a comfort in knowing that you're stable, but I am always still waiting for the other shoe to drop.

I currently undergo scans every 6 months, which is always nerve wracking, but I would prefer to keep the 6 month scans over the 9 month scans so that I am being closely monitored and we are aware as soon as possible if anything changes.

My experience with side effects has been tolerable, I have not experienced the horrible diarrhea that some patients complain about being on this therapy. I have had GI issues, but they have been mostly manageable. After being on this therapy for 6 years I have learned how to manage these side effects and also prepare for sudden onset. For example I will always bring Imodium and anti-nausea medication with me when travelling. I also experience joint pain and fatigue, but I think a lot of those side effects are from the letrozole.

I do find the side effects mostly manageable and acceptable considering that these therapies have been effective of stopping the progression of the cancer. I have taken a short break a couple of times over the past few years due to side effects building up; because abemaciclib dosing is daily, with no breaks, taking a short break helped reset my system and give me enough of a break that the side effects then became manageable again. One of the breaks I took was because I was nauseous all the time, and just taking a short time off treatment resolved this, and when I started taking treatment again the nausea had subsided.

I have been very fortunate to have an oncologist who is very familiar with this treatment and who has been willing to work with me to adjust doses, take treatment breaks, to help manage side effects. I did have a dose reduction fairly early on in treatment due to white blood counts that were too low. I am now taking 100mg twice a day and this has been a well tolerated dose that also continues to work.

I was working full time when diagnosed and have been able to continue to work full time while receiving treatment. I have been very private about my diagnosis, so many of the people I work with don't even know that I had this diagnosis. I am currently taking a break from work as I was finding that the fatigue I was experiencing was hard to manage working full time and also managing all of the things in my personal life, like having two teenage boys at home, and running a household.

Because this is an oral treatment this has made a difference in my ability to work and also participate in regular life activities. I'm not having to go to the hospital all the time for treatment, I'm not having to schedule my travel around frequent treatments. This flexibility has really made a difference in my ability to just live my life.

I have also been fortunate that my treatments have been covered through insurance and through support from the manufacturer. I feel for patients who are having to pay out of pocket as the cost can be unmanageable.

I think this is an important treatment for others to have access to. We know that treatment options are important; we all follow the trails, and are looking at which CDK4/6 inhibitor is doing better, but we also know that some drugs work better than others for different people. There are reasons why one therapy may be a better choice for a patient and it's important the doctors and patients have the choice to take a medicine that is the right fit for that patient.

I have been able to generally live my life and do all the things that I want to do. I have two busy teenagers that I am able to be there for; we regularly travel as a family, having just gone to Hawaii for two weeks, and also visiting Europe to see my husbands' family.

Patient 2: Laura

I started treatment for stage 4 breast cancer in May 2024, I am on 50mg of Verzenio two times a day and also faslodex. The first scan (left) is when I was initially diagnosed in May 2024, the second scan (middle) is from September 2024, and the third scan (right) is from January 2025. As you can see from my scans, nearly all my mets are gone.



I did have side effects when I started treatment, mainly diarrhea, and xgeva gave me fly type symptoms for a couple of treatments but now I'm feeling pretty good. Prior to starting treatment I had a bad cough and was very stiff, but since going on treatment I feel very healthy. It thought it was a death sentence when I was diagnosed but having access to these new drugs, they work! I'm able to continue to go on holidays, I'm retired and have been living my life. Everyone should be able to access these treatments.

Patient 3: Heather

I was first diagnosed with HR-positive early-stage breast cancer in 2004. I was later diagnosed with metastatic breast cancer in 2010. My metastatic breast cancer was HR-positive, HER2-negative, we have since learned that it's actually HER2-low but at the time of my diagnosis we were not aware of HER2-low. At the time of this interview I have been living with metastatic breast cancer for 15 years and am currently on my 15th line of treatment. I have lived in Toronto, Calgary and Ottawa during this time and have travelled to different cities in Canada and the US to access various clinical trials.

While being treated for metastatic breast cancer I continued to work up until 2020, which was through 10 lines of treatment.

I was able to gain compassionate access to Verzenio as my 11th line of treatment in 2020. I started on 200mg per day but the GI issues were very significant, so I reduced which made it much more tolerable and I was able to be on this treatment for a year before it stopped working. Even being heavily pre-treated, this treatment worked for me for a year.

Patient 4: Mary

I was diagnosed with early-stage breast cancer in 2013 and then recurred in December 2022. I had lobular breast cancer both times and was diagnosed with skin metastasis and bone metastasis on my second diagnosis.

I have been taking Verzenio and letrozole as my first line of treatment, which I started in January 2023. A PET scan showed a small lesion in my brain, and I had surgery to remove this lesion, this is why my oncologist selected Verzenio because it crossed the blood brain barrier. There has been no evidence of disease since my first scan, after taking Verzenio and letrozole, so the treatment has been working as far as managing my cancer.

I started on the original dose but experienced severe diarrhea, to the point where it was almost impossible to go anywhere as I need to be close to a bathroom. The dose was lowered to 150mg per day, and then eventually to 100mg per day, but instead of taking it all at once I take 50mg twice per day, which has made a difference in terms of managing issues I had with diarrhea.

I am still experiencing other side effects, but I think they're mostly from the letrozole; this includes osteo-arthritis, brain fog and joint pain. I used to write and do a lot of genealogy research, but this has come to a halt due to the brain fog and the fatigue. My physician referred me to a palliative clinic to help with some of the side effects, including speech therapy to help with the brain fog.

I am really grateful that my cancer is stable right now. I am hopeful that even if my cancer progresses on this treatment that there are other drugs in development that will continue to help manage it.

7. Companion Diagnostic Test

Testing required for this treatment is already accessible and covered in jurisdictions across Canada.

8. Anything Else?

Patient/physician choice is an important part of treatment. Our health system recognizes that patients need personalized approaches to care that take into consideration the individual as a whole, the specifics of the biology of their tumour, co-morbidities, preference when it comes to side effects, and the dosing schedule. By restricting funding for drugs, that have the efficacy data to support their usage, we are restricting some patients from receiving optimal care. Health care professionals should be able to tailor treatment plans to best meet the needs of their patients, and by restricting reimbursement for some therapies, the health system is creating a barrier for patients.

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
Lilly 2024			x	
Lilly 2023			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: Jenn Gordon

Position: Lead Strategic Operations and Engagement

Patient Group: Rethink Breast Cancer

Date: February 28, 2025

APPENDIX A: MBC Patient Survey Results

Information for this report was gathered through an online survey published in English and circulated through communications from Rethink Breast Cancer as well as the Rethink Network and other partner organizations. Messages were also posted on Facebook and Twitter as well as the Breastcancer.org, Cancer Connection and Cancer Survivors Network online discussion forums. 78 metastatic breast patients completed the survey between September 2018 and April 2019.

Rethink Breast Cancer asked respondents to evaluate the importance of different outcomes for their breast cancer treatment on a scale of 1 (not important) to 5 (very important). All the listed outcomes were considered important with no average scores lower than 4.4. However, controlling disease and extending life expectancy were rated as the most important results suggesting that patient values prioritize long-term health outcomes over immediate concerns like reducing symptoms or managing side effects.

Importance of outcome	1 – not important	2	3	4	5 – very important	Average
Controlling disease progression	0.00% 0	0.00% 0	0.00% 0	2.60% 2	97.40% 75	4.97 77
Reducing symptoms	1.30% 1	0.00% 0	12.99% 10	19.48% 15	66.23% 51	4.49 77
Maintaining quality of life	0.00% 0	0.00% 0	1.30% 1	12.99% 10	85.71% 66	4.84 77
Managing side effects	1.30% 1	1.30% 1	12.99% 10	19.48% 15	64.94% 50	4.45 77
Achieving NED (no evidence of disease)	1.32% 1	1.32% 1	1.32% 1	6.58% 5	89.47% 68	4.82 76
Extending life expectancy	0.00% 0	0.00% 0	0.00% 0	2.63% 2	97.37% 74	4.97 76

Comments included:

- Symptoms and shrinking the cancer is the most important thing. Living well is the next most important thing.
- Keep me alive for my kids.
- I want to live, LIVE and enjoy my life for many more years and not be so afraid.