

## Patient Input Template for CADTH Reimbursement Reviews

Name of Drug: abemaciclib (Verzenio)

Indication: Eli Lilly Canada Inc. (Eli Lilly) is requesting reimbursement for Verzenio (abemaciclib), in combination with endocrine therapy for the adjuvant treatment of adult patients with hormone receptor (HR)-positive, human epidermal growth factor receptor 2 (HER2)-negative, node-positive, early breast cancer at high risk of disease recurrence based on clinicopathological features and a Ki-67 score  $\geq 20\%$ .

Name of Patient Group: Rethink Breast Cancer

Author of Submission: MJ DeCoteau

### 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 40 individuals that we work extremely closely with as key patient advisors; the 100 patients that share their stories on our blog; the 500 patients that participate in our virtual support groups; the 1,600 members of our private peer-support network; the 30,000 people that have joined our Instagram community; and the 150,000 individuals reached each month through the reach of that channel. We listen, learn, engage and have conversations in all these spaces.

Rethink Breast Cancer has several important patient advisory boards and working groups that offer experience-focused insights on issues related to those affected by and concerned about breast cancer, including:

- Metastatic Breast Cancer Advisory Board
- Early Breast Cancer Advisory Board
- Equity, Diversity and Inclusion working group
- Triple Negative Breast Cancer working group (all stages)

For this submission, we have drawn on our general observations and insights gathered through programming and meetings with breast cancer patients as described above. Rethink also conducted in-depth telephone interviews in March 2022 with two patients who have experience with abemaciclib for HR+, HER2- high risk early breast cancer, and one patient who has been prescribed it by her oncologist but, two months later, was still waiting to start it.

## 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 takes on a young person's life is devastating and traumatic.

When it comes to those in the community who have been told their breast cancer is at a high risk of recurrence, treatment is less about controlling an aspect of the illness and more a deep desire to take on whatever treatment(s) are needed to decrease the chance of recurrence and metastasis. They are facing mortality prematurely and many express a goal to treat aggressively to optimize treatment. Those we interviewed in March for this submission shared:

*"I think when anyone gets a cancer diagnosis, you're always scared of the illness coming back. Especially when I have young kids that I want to be there for, and I have a lot of things I want to do myself. It's not only my kids, but also my life too. I want to be able to enjoy it. Because I feel that I'm doing anything and everything that's available out there to have a lower chance of recurrence, it gives me peace of mind. It gives me less anxiety in my life." –Negar*

*"I am generally a fan of treatment – the more aggressive the better. In fact, after having chemo done, I advocated to have a total axillary LN dissection, and I also had my ovaries out last year. Again, I don't mind treatment at all, even the side effects that come with it – I'm more concerned about the prospect of mortality." –Ada*

*"I want to try anything to prevent recurrence, I want to add it to my exercise routine and healthy diet in my bag of tricks." –Jessica*

#### 4. Experiences With Currently Available Treatments

Current treatment for HR positive HER2 negative early breast cancer depends on the details of the person's diagnosis and the characteristics revealed on their pathology report. It is usually treated with a combination of surgery, chemotherapy, radiation therapy, and hormonal therapy, which can reduce the risk of early-stage breast cancer coming back. Some patients will opt for an oophorectomy. These treatments are all incredibly difficult with both physical and emotional impacts that require a lot of support and care. Peer support is incredibly helpful as is professional support. Being well prepared for what you are about to endure is essential and oncology nurses and a peer community are extremely helpful in this regard both with short term and long-term side effect management. Difficulty coping with the side-effects of hormone therapy is frequently discussed in our community.

## 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. In our experience working closely with many young high risk breast cancer patients, we find most are willing to trade toxicity for confidence in knowing they've "thrown everything they could" at the cancer. In other words, they will choose to endure additional side-effects and impacts on quality of life from the toxicity of a stronger therapy to ensure they are doing everything they can to treat what they know is an aggressive form of breast cancer. That was a take-away from the patients we interviewed for this submission who are on Verzenio and the one that has been prescribed it and is waiting. We've also had patients in the community reaching out to our organization, asking when it will be available in Canada for early breast cancer.

## 6. Experience With Drug Under Review

Rethink conducted in depth phone interviews with two patients with high-risk early breast cancer who have experience with abemaciclib (Verzenio). We also interviewed one person whose only experience with Verzenio was that she'd been prescribed it by her oncologist over two months ago and was still waiting to start it as she deals with navigating the challenges of her insurance's heavy co-pay.

### Patient 1 interview: Negar

*My name is Negar. I'm located in Vancouver, BC. At the end of my pathology report, I was Stage 2B. I was 39 at the time. I had three tumours. I found it myself. We never had any family history. The lump was moving. My family physician was sure that it wasn't cancer, but she just wanted to make sure and have peace of mind, so she sent me for testing and here I am. I did surgery first and then 8 rounds of chemo, 25 rounds of radiation. I did an oophorectomy. At the beginning I was going to do Zoladex, but I talked with my doctors, after 10 years I'll be almost 50 so there was no point for me to stay on Zoladex, so I did an oophorectomy in March.*

*In regards to my treatment path, I wouldn't say hell, although I had days that looked like hell. I was lucky I caught it early. I had node involvement and normally when there's a lymph node involvement it spreads quickly after that. It was a lot of ups and downs; I still have a lot of that. Sometimes I think I came to terms with it, but I don't think I have yet. It was very scary as I have 2 young children. I was working full time. I always say it was my prime time with my kids and my work, but I had to put everything on pause. It's a scary, scary situation to be in because you see so many people that had the same diagnosis, they got the same care, but they had a recurrence. So, when my doctor talked about Verzenio although the side effects are not something that I look forward to, but again it's bringing the possibility of recurrence lower, so I take it.*

*I was really lucky that my oncologist referred me – I think the manufacturer is the one paying for me, I'm not paying out of pocket. Here it's \$13,000 per month and I definitely cannot afford that. I was very concerned about the cost. Maybe if I didn't have kids, it would be a totally different experience. I had a cousin; she was like my sister. She was 5 years younger than me. She passed away from ovarian cancer in 2019, so we had that scare in our family. Not in a blaming way, but one thing that everyone thought is that she didn't take the cancer seriously. So, from the minute I was diagnosed, I was quite proactive on finding the best solution. When I was talking with my oncologist, I already had done tons of research on breast cancer, what treatments are available, my second opinion from MD Anderson, etc. So, when the Verzenio got approved by Health Canada, I knew about it, I read about it, I did research. I follow quite a few of women with breast cancer on Instagram and I saw them talking about it and the cost of it. So, the cost was something that I was concerned about. \$13,000 a month is a lot of money. Both my husband and I are making good money, but this is still a lot of money per month. We thought, we're going to try to do this, and even if we have to remortgage our house to get the money from the equity in our house to pay for the treatments, we're going to do it.*

*My oncologist was on board for me taking this medication and said there's ways it can be covered. Thankfully I was approved for it. So, I feel very blessed and lucky that this treatment was available to me for free. I understand some provinces don't cover oral chemo and it's scary. Especially with cancer, time is of the essence. You need to be very quick. You cannot wait a year for this to become available because in that year, the cancer might spread and turn metastatic.*

*I feel so lucky that I have access to it at no cost. But the side effects, I haven't had severe ones yet. I'm very tired, but I'll take being tired rather than the cancer coming back. I think when*

*anyone gets a cancer diagnosis, you're always scared of the illness coming back. Especially when I have young kids that I want to be there for, and I have a lot of things I want to do myself. It's not only my kids, but also my life too. I want to be able to enjoy it. Because I feel that I'm doing anything and everything that's available out there to have a lower chance of recurrence, it gives me peace of mind. It gives me less anxiety in my life.*

*I would absolutely recommend Verzenio to other patients in my position. This is \$13,000 per month. But what if the illness relapses? If you compare the amount of emotional distress and money that they're going to put the family through with loss of life, other chemo, hospice, etc. so many things. When I got diagnosed with breast cancer in Canada, I felt so lucky because finances weren't something I had to worry about. Of course, we were losing my income, but I didn't have any extra costs. But this is the extra cost. If the Canada doesn't fund this, I cannot imagine this stress in having the thought that something was available to me, and I wasn't able to access this because I didn't have the financial resources. It's not fair.*

#### Patient 2 interview: Ada

*I am 36 years old and was diagnosed with breast cancer when I was 33 years old. I had hormone positive and receptor negative type. I had my double mastectomy first, and my lump was 4.3cm! with 3/4 sentinel lymph nodes positive. I live in Richmond BC. I'm a social worker at a very large long term care home in Richmond. Being sick during the COVID 19 pandemic meant that I wasn't able to be at work during a time when they really needed staff and that was hard. I have a 4-year-old and 6-year-old now.*

*I didn't mind the treatment because for me, having treatment was taking action. I don't mind treatment at all, even the side effects that come with it - I'm more concerned about the prospect of mortality. My oncologist, who I trust, thought Verzenio would be good for me, so I didn't even hesitate to say yes. As long as it doesn't make my Anastrozole less effective, then I'm game - always.*

*The Lilley program is paying for my Verzenio. My extended health from work doesn't cover it. The pharmacy that it comes from has been good too. I just don't like that they deliver it monthly because it's a hassle to coordinate, and I'm always worried that something will happen where I don't get my next delivery. I was expecting to get diarrhea my first week, so I took Imodium but then I ended up with constipation for like a week. Now my body has gotten used*

*to it. I still get the occasional cramping or bloating, but nothing I can't tolerate. I would say though, for people just starting on Verzenio that I think once your body adjusts to it, it gets better. The first couple of weeks can be rough.*

*I would recommend Verzenio. Patients should never have to worry about getting their medications through bureaucratic processes. Please make life easier for patients than they already are. Provinces should fund this medication and make it easy for those who fit the criteria to get it.*

### Patient 3 Interview: Jessica

*I am currently 41 years old, having just passed the one-year anniversary of my diagnosis in April 2021. I live in Ottawa with my husband and our 7-month-old son. I work at Global Affairs Canada in the Foreign Service, so I was actually diagnosed in Brazil and came home immediately to start treatment. I was also 15 weeks pregnant while diagnosed.*

*I'm not sure where to begin. Diagnosed with IDC, stage 2B, HR+, PR+, HER-. I started Chemo in April, AC-T dose dense protocol. I finished in August and had a few weeks to recover before my son was induced at 38 weeks which resulted in a c-section. From there I had a lumpectomy, balancing reduction and a SLND a little over a week after the birth of my baby. My margins did not come back clear and there was a significant number of affected lymph nodes. The pathology report was fairly damning. My Ki score was very high. I had surgery again a few weeks after the first, this time a mastectomy and a complete lymph node dissection. I followed with 15 rounds of radiation. I have been, and continue to be, terrified I will not be able to watch my son grow-up. It is my constant worry.*

*My oncologist told me about the success of the Monarch E studies and the announcement in the US came right around the same time as my pathology report. It gave me hope that my cancer, at very high risk for recurrence, could be kept at bay. I want to try it because I want to try anything to prevent recurrence, I want to add it to my exercise routine and healthy diet in my bag of tricks.*

*I am still waiting to access Verzenio. My oncologist prescribed it two months ago. I do have private insurance but the additional 20% is still quite steep. My understanding is that the hospital is trying to sort out the payment plans.*

*It is not an easy treatment and there are many side effects, but it could allow people like me to do everything possible to prevent recurrence. From a purely financial perspective, the medication is expensive, but the cost of treating MBC, or even just a second early-stage cancer, paired with 20 potential years of lost employment/productivity is a heavy burden as well.*

## 7. Companion Diagnostic Test

Nothing to report on this topic.

## 8. Anything Else?

We'd like to emphasize that young, high-risk breast cancer patients want more effective tools in their toolbox that will help improve their chances against this challenging disease that's turned their life-plans upside-down.

As we ponder "anything else," we think about the MBC community that we know so well—and their loved ones. We think about those we've lost. Too, too many at such a young age over the years. Their families will never be the same. We also think about the MBC community that we see currently thriving. The CDK 4/6 inhibitors have been more of a game-changer in our community than we could have ever imagined. That said, moving the needle on MBC outcomes is still not the same as a cure. Verzenio as an option for those with HR+ HER2- breast cancer that is at a high risk of recurrence can give patients a tangible way to help achieve their goal of a cure.

And, finally, as we have been in the thick of #BitterestPill, an advocacy campaign calling for equal funding for Take Home Cancer Treatments in Ontario, we think about the delays, dollars, distress and discrimination that the current program in Ontario entails, which negatively impacts patient outcomes. Many in our community are underinsured and uninsured and our hearts go out to Jessica, who has been waiting two months to start the Verzenio she was prescribed by her oncologist because of the cost of her insurance co-pay. Too many are impacted by a policy that's needed updating for over a decade!

## 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
Eli Lilly 2021			X	
Eli Lilly 2020			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:** MJ DeCoteau

**Position:** Founder and Executive Director

**Patient Group:** Rethink Breast Cancer

**Date:** April 14, 2022