CADTH Reimbursement Review
Patient Input Template

Name of Drug: Perjeta (pertuzumab)
Indication: Perjeta in combination with trastuzumab and chemotherapy for the neoadjuvant treatment of patients with HER2-positive, locally advanced, inflammatory, or early stage breast cancer
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.

For this submission, we have drawn on our general observations and insights gathered through programming and meetings with breast cancer patients as described above.

We also gathered information through an online patient survey that was conducted from March to April 2021 for Rethink's initial submission to CADTH for Perjeta in the neo-adjuvant setting. The survey asked questions about the impact of breast cancer on the lives of patients, the effect of current treatments and their willingness to possibly manage additional side effects for improved health outcomes. The survey also included questions specifically about Perjeta. Respondents were identified through Rethink's community reach, mentioned above. A total of 62 women completed the survey, 37 were from Canada, 22 were from the United States, and 1 was from Mexico, Macedonia and Portugal, respectively. Of those 62 women, 35 had experience taking Perjeta. Additionally, 7 of the women from this survey were further interviewed by Rethink Breast Cancer to discuss their treatment experience and elaborate on their feedback.

Rethink also conducted in-depth telephone interviews in February 2025 with two patients who more recently accessed or tried to access Perjeta. One was able to access Perjeta for early-stage breast cancer and one who had challenges accessing it due to the lack of provincial reimbursement.

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.

Tabitha, a patient interviewed for this submission shared the following about being diagnosed with breast cancer as a young woman:
"The recurrence rate with HER2-positive breast cancer is high, why are we not offering everything we can to help reduce the risk of recurrence? Why are we not giving patients access to new treatments earlier, that can help prevent recurrence, that can help reduce the need for more treatments later on, that can actually reduce how much we're using the health system in the long run?"

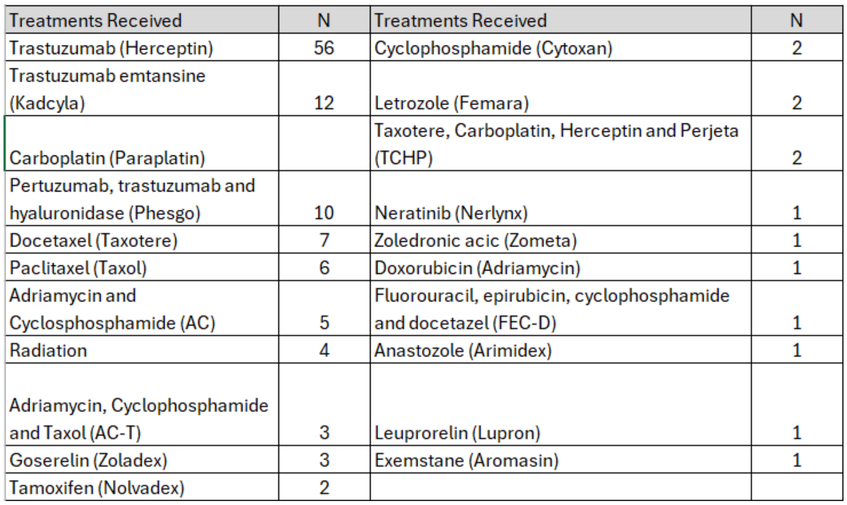
Another patient, Negar, diagnosed with early-stage breast cancer, shares the following:
"I think when anyone gets a cancer diagnosis, you're always scared of the illness coming back. Especially when you have young kinds that I want to be there for, and I have a lot of things I was to do myself. It's not only about 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."

And finally, Jessica, another woman diagnosed with early-stage breast cancer, sums it up succinctly:
“I want to try anything to prevent recurrence.”

With Currently Available Treatments

Current treatment for HER2+ early-stage breast cancer typically consists of a combination of targeted therapies such as Herceptin, chemotherapy, radiation therapy and survey. These treatments can be difficult in terms of the physical and emotional impacts. Along with supportive medications to help manage the side effects of treatment, patients may also benefit from peer support and professional psychosocial support to help manage the impact of treatment and of a breast cancer diagnosis.

In the survey that was conducted in 2021, all 62 respondents provided information about the treatments they had undergone since their diagnosis. Herceptin was the most commonly received form of treatment.

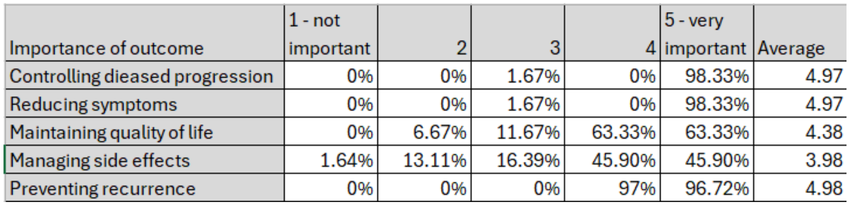


Treatments Received	N	Treatments Received	N
Trastuzumab (Herceptin)	56	Cyclophosphamide (Cytoxan)	2
Trastuzumab emtansine (Kadcyla)	12	Letrozole (Femara)	2
Carboplatin (Paraplatin)		Taxotere, Carboplatin, Herceptin and Perjeta (TCHP)	2
Pertuzumab, trastuzumab and hyaluronidase (Phesgo)	10	Neratinib (Nerlynx)	1
Docetaxel (Taxotere)	7	Zoledronic acic (Zometa)	1
Paclitaxel (Taxol)	6	Doxorubicin (Adriamycin)	1
Adriamycin and Cyclosphosphamide (AC)	5	Fluorouracil, epirubicin, cyclophosphamide and docetazel (FEC-D)	1
Radiation	4	Anastozole (Arimidex)	1
Adriamycin, Cyclophosphamide and Taxol (AC-T)	3	Leuprorelin (Lupron)	1
Goserelin (Zoladex)	3	Exemstane (Aromasin)	1
Tamoxifen (Nolvadex)	2		

Fatigue was the most commonly reported side effect of these treatments (80%, n=62), followed by diarrhea (64%), nausea (44%), and insomnia (39%). Fatigue was most frequently cited as the hardest to tolerate side effect of these treatments. Diarrhea, nausea, neuropathy and taste changes were also cited by at least 10% of the respondents.

5. Improved Outcomes

In Rethink’s 2021 survey, we asked patients to evaluate the importance of different outcomes for their breast cancer treatment on a scale of 1 (not important) to 5 (very important). Eliminating cancer cells, preventing recurrence and preventing metastases were overwhelmingly rated as the most important results suggesting that patient values prioritize long-term health outcomes over more immediate concerns like reducing symptoms or managing side effects.



Importance of outcome	1 - not important	2	3	4	5 - very important	Average
Controlling dieased progression	0%	0%	1.67%	0%	98.33%	4.97
Reducing symptoms	0%	0%	1.67%	0%	98.33%	4.97
Maintaining quality of life	0%	6.67%	11.67%	63.33%	63.33%	4.38
Managing side effects	1.64%	13.11%	16.39%	45.90%	45.90%	3.98
Preventing recurrence	0%	0%	0%	97%	96.72%	4.98

Respondents were also asked if they would be willing to tolerate new side effects from new drugs to extend life expectancy. On a scale of 1 (will not tolerate side effects) to 10 (will tolerate significant side effects), respondents gave an average score of 8.57, supporting the conclusion that patient values prioritize health outcomes. It should be noted that patients who received pertuzumab gave an even higher score of 8.8.

Comments included:
" I am willing to suffer side effects if there is solid evidence that it will eliminate cancer cells and prevent recurrence. The fear of recurrence is a burden that cancer survivors need to live with every day."

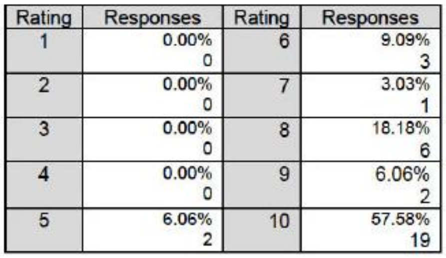
"I will tolerate whatever symptoms I have to so that I can survive and take care of my children."

"This is rough to answer. I just finished chemo and feel like there's no way I'd ever do it again. Period. But at the same time how do you not do "whatever" it takes to stay alive? I'd undergo near death side effects in order to avoid death."

6. Experience With Drug Under Review

Of the participants in the 2021 survey, there were 35 who met the full indication for this submission; they were diagnosed with locally-advanced, inflammatory or early-stage breast cancer and received Perjeta in combination with trastuzumab and chemotherapy in the neo-adjuvant setting. Out of the 35 respondents, 21 achieved a pathological complete response, 1 did not receive a pathological complete response, and 13 were unsure or did not answer.

Diarrhea and fatigue were the most commonly reported side effects from the 35 survey respondents. However, respondents overwhelmingly described these side effects as tolerable. When asked how much they could tolerate the side effects associated with Perjeta on a scale of 1 (completely tolerable) to 10 (completely intolerable), the average score was 8.82 with no respondent giving a score lower than 5. One patient commented that, "compared to the first chemo I was on, the side effects were minor". Another patient noted that it was "totally worth it".



Rating	Responses	Rating	Responses
1	0.00% 0	6	9.09% 3
2	0.00% 0	7	3.03% 1
3	0.00% 0	8	18.18% 6
4	0.00% 0	9	6.06% 2
5	6.06% 2	10	57.58% 19

Several respondents also emphasized that they were willing to tolerate the side effects associated with Perjeta because of the value it offered in terms of risk reduction:

- Even if there were stronger side effects, I think they would have to be pretty severe for me to have wanted to stop taking [Perjeta].

- Anything that's led to my pos-op NED result was well worth it
- IF you have a scan or you and another ultrasound and you see the reduction in the tumour so quickly, it had an impact on anxiety, on positivity, on quality of life
- Symptoms are temporary, I would rather not feel well for a short term and be here cancer free for the long term

Some respondents also commented on the benefit of having a targeted treatment for HER2-positive breast cancer:

- Knowing that it's out there, it was great to have access to something that partnered so well in targeting the HER2 factor
- As soon as I saw the studies that said the dual-targeted therapy for HER2 gives you an added benefit in the neoadjuvant and adjuvant setting, I wanted to have it for myself.

Rethink more recently, **February 2025**, **spoke with two patients who had accessed, or tried to access, Perjeta.** Their experience is captured below:

Patient 1: Nicole (able to access Perjeta through private insurance and manufacturer assistance)
I was diagnosed with breast cancer in February 2023, at the age of 33. I was initially told by my primary care physician, who had sent me for imaging and then eventually a biopsy because of a lump that I found on the side of one of my breasts. I first met with my medical oncologist in March, who put together a treatment plan, but because the cancer was found in my lymph nodes and was not actually in any of my breast tissue, deciding on the right treatment and even the staging of the cancer took longer than usual.
When my pathology finally came back it showed that I had HER2-positive and ER-positive breast cancer, this is when my medical oncologist spoke to me about adding Perjeta in the neo-adjuvant setting. I was already scheduled to receive chemotherapy neo-adjuvantly. Because Pejeta wasn't covered by the province, I was told that I would have to go to a different clinic to receive that treatment. The team at Princess Margaret Hospital was incredible at filling out all of the paperwork needed to set up this treatment at the other clinic and coordinate coverage for the cost of the treatment. My private insurance paid for some of the cost of Perjeta and the manufacturer paid for the remaining cost.

I was very fortunate in that I was working as an independent contractor with my employer at the time I was diagnosed, and they expedited the process of bringing me on as a full-time permanent employee so that I could access the full benefits package to help support me through this diagnosis as much as possible. If I had not been able to have this covered through my private insurance and with the help of the manufacturer, I would have had to figure out how to come up with funds to cover the cost of this treatment. This would have posed significant financial challenges as I am a single income household and have a mortgage to pay.
Because I live downtown, both the hospital and the private clinic for Perjeta were located within walking distance, so having to go to two different locations wasn't a major inconvenience; however, I could see this being a challenge to people who aren't located as centrally and need to travel further distances to access a private clinic.
I received 4 or 5 rounds of Perjeta during the same period that I was receiving chemotherapy. The main side effect I noticed from Perjeta was fatigue right after the infusion. I walked to all of my appointments and did notice on the walk home after the fatigue setting in. I was however able to work all through my treatments, while taking chemo and Perjeta.

I had surgery in August 2023, and 13 lymph nodes were removed. I could physically feel the tumour shrinking as I was taking chemo and Perjeta, and when I went for surgery all that remained on the affected lymph nodes where the cancer was, was scar tissue. The cancer responded well to the neo-adjuvant treatments.

I did radiation post surgery, and am currently taking tamoxifen, although we're trying to figure out if that's actually going to help reduce my risk given my estrogen receptor positivity.

I was very fortunate to have the support of my employer to be able to access Perjeta without paying out of pocket costs, this would have been an incredible barrier to accessing that treatment. Every person should have access to life saving treatment, and treatments that can reduce your risk of recurrence. People in this position are scared; you don't know what the future holds, and it's really important for people to have equitable access to treatments that can improve health outcomes.

The mental health aspect of navigating a cancer diagnosis and treatment is understated, and the additional financial burdens create a significant impact on mental health. I can't imagine having to go through that additional financial stress of trying to pay for a treatment, while also dealing with a cancer diagnosis. No one should have to experience this during one of the most vulnerable moments of their in life.

Patient 2: Tabitha (challenges accessing Perjeta due to cost and lack of coverage)
I was diagnosed with HER2-positive breast cancer when I was on maternity leave with my second child in 2023. Initially it was thought that I had stage 2 breast cancer, and because I was born with a heart condition, my medical team was concerned about using the standard of care chemo because of my heart condition. They recommended using a different type of chemo, and to make it more effective they wanted to add on Perjeta.

Because Perjeta was not publicly funded in Ontario, I was given paperwork to submit to my private insurance to see if they would cover the cost. I am a teacher, and have good benefits, but my insurance denied this claim. I was told that it would cost me $4,000 out of pocket to access this treatment that was necessary to best treat my breast cancer and give me the best chance of reducing the risk of recurrence. I was on maternity leave and had two children at home; my husband works full time at a good job, but $4,000 a month is not something that we could cover. I didn't want to crowd fund my treatments. I was put in touch with the Trillium fund to help reduce the cost, but it was still going to be $2,000 per month which was still not financially feasible being on maternity leave.
As if dealing with a breast cancer diagnosis as a young mom wasn't enough, I was also left trying to figure out how I was going to pay for the treatment that my medical team thought was the right treatment for me. I was scrambling to get all the information and paperwork needed from my oncologist to appeal to the insurance company which was incredibly stressful and exhausting at a time when I was already overwhelmed. There's nothing worse than hearing, "hey, we think we can save your life, but it's going to cost you", and knowing that cost is completely out of reach. While I was trying to go through the insurance appeals, and piece together enough funding sources to cover the treatment, I was also trying to coordinate logistics with my cancer centre about where I would actually receive the treatment. Because Perjeta would be privately funded I would have to go to a private clinic to have it administered. I was also left trying to coordinate with the hospital the logistics of trying to get a cold cap machine from the hospital over to the private clinic.

Because I have a genetic heart condition that I was born with and couldn't have the standard of care, I was forced to decide whether or not to go into considerable debt to have the treatment I needed. We hear so much talk about precision oncology, but the system has these ridged barriers that don't actually allow for precision oncology. There are so many nuances in treating patients with the best individualized care, but there isn't the flexibility in the system to make this a reality.

I don't understand why, with all the data that supports the use of Perjeta for early-stage patients, that it isn't covered? I wanted to be able to take whatever medications I could to give myself the best chance for a cure and for not having a recurrence, and I was being restricted from doing so by a system that was supposed to help me.
I have dealt with the health system for epilepsy, I have a heart condition I was born with, and have interacted with the health care system with so many other health issues, and I always felt that I had the care that I needed. But dealing with cancer, everything is so RIGID. There is NO flexibility. People can't actually get the treatments they need. Having co-morbidities adds another layer of complexity and the system is so rigid that it doesn't allow for the flexibility to actually treat patients as individuals.

The recurrence rate with HER2-positive breast cancer is really high, why are we not offering everything we can to help reduce the risk of recurrence? Oncologists want access to this therapy for their patients, why are we not listening to the experts that are treating patients every day? Why are we not giving patients access to new treatments earlier that can help prevent a recurrence, that can help reduce the need for more treatments later on, that can actually reduce how much we're using the health system in the long run?
Perjeta should be an option for every HER2-positive early-stage patient. Patients want to do everything we can to get our lives back. It's better for patients and for society as a whole; we want to be able to contribute to society, to be less of a burden on the health care system; why is the system not paying for treatments that allow us to make that a reality?

Before I could start Perjeta for early-stage breast cancer, my PET scan results came back and showed that the cancer had actually metastasized. The irony was that my Perjeta would now be covered, although this wasn't communicated to me until I was about to start treatment.

I have been taking Perjeta for HER2-positive metastatic breast cancer since October 2023. I appreciate that this submission isn't about taking Perjeta in the metastatic setting, but given my experience trying to access it in the early stage setting I wanted to share what the lack of funding is doing to patients. My experience taking Perjeta has been that it's fairly tolerable. Most of my treatment side effects subsided once I was done chemo and just continued on Herceptin/Perjeta. Generally, my quality of life is pretty good, on the day that I receive treatment I feel a bit off, but other than that I have a good quality of life. I know a lot of patients experience challenging GI issues, but this generally hasn't been my experience, I've been able to have a good quality of life. I had some digestive issues earlier on but those seem to have gone away. I do experience dry eyes, but I think that's from the Herceptin.
I have been trying to access another drug, tucatinib, for my metastatic breast cancer, that helps prevent brain metastasis, but it also isn't covered. And while I've been waiting, trying to figure out how to get it covered, I have had a small lesion appear in my brain. I have since undergone GammaKnife radiation therapy, but can't help but wonder if access to tucatinib would have prevented this.

First the system failed me when I found a lump and wasn't taken seriously. And now I'm navigating a system that is designed with a "one size fits all" approach and wants patients to fit in a nice tidy box. There's so much more time that I could be spending with my kids, or trying to get back to work, instead of having a full-time job of being a cancer patient and trying to get medications that have proven efficacy.

Patients want to pay bills, we want to work, we want to pay taxes, if there's a medication that could be helping us get our lives back, that is a proven treatment, why aren't we able to access it? We need to do a better job of catching up to the rest of the developed countries. Why is Canada lagging behind? I have a young family, I don't have the ability to travel to the US to access treatments while I wait years for them to be approved here in Canada. Why are we increasing barriers for people who don' have the financial ability to pay out of pocket? It's supposed to be health care for all in Canada, and my experience has been that it really is not.

7. Companion Diagnostic Test

Testing needed to determine eligibility is already available and funded in all jurisdictions.

8. Anything Else?

In a country with universal health care, access to optimal care is supposed to be equitable. The current lack of public reimbursement for Perjeta for the treatment of early-stage breast cancer is just one example of the barriers that are creating gaps in care for Canadians. People diagnosed with cancer should be able to access treatments that have evidence clearly showing the ability to reduce the risk of recurrence. Treating cancer at an early stage and reducing the risk of recurrence is what's best for patients, families, communities and the health system as a whole. Investing in these treatments up-front and reducing the risk of later stage diagnosis will benefit everyone in the long run.

Appendix A:

We invite you to learn more about some of the patients who contributed to this submission in Appendix A.

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
Roche 2024			X	
Roche 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 & Engagement
Patient Group: Rethink Breast Cancer
Date: February 26, 2025

Appendix A:

Nicole and Tabitha shared their experience with Perjeta, but are also more than their cancer diagnosis. Learn more about their WHY!

Nicole

Nicole (she/her) is just an Aries girl living and working in Toronto, ON. In February 2023 Nicole received life-changing news, and spent the next 16 months receiving treatment at PMCC for her stage 2 Her2+ ER+ BC.

Nicole has spent the last 10+ years as a communications professional specializing in PR for lifestyle and beauty brands before entering the healthcare communications space in 2021. In her work for a local hospital, she has supported mental health education and scientific literacy through partnerships that promote increased access to mental health resources and learning tools. Since her diagnosis, Nicole has shared her experiences navigating life, work, relationships, and the healthcare system as a young Black woman with BC.

Nicole has a love for pop culture and her favourite shows to watch include RuPaul's Drag Race and Survivor. Nicole likes singing in the shower, baking treats to eat because #girldinner, and saying hi to dogs while out for walks in her neighbourhood. Her favourite foods include pizza and tacos, and she has seen The National play live more times than she can count. When Nicole is not working for the #MentalHealthIsHealth movement, Nicole can be found on FaceTime with one of her friends or on a plane somewhere.

Tabitha

Tabitha is an elementary school teacher from Toronto and mother of two busy boys (ages 5 and 2). She found a lump while breastfeeding, but she faced many hurdles to get it checked out properly. She was diagnosed while on maternity leave with De Novo ER-/PR-/HER2+ Metastatic Breast Cancer at the age of 40. Now one year into her diagnosis, she has been focusing on advocacy, including co-creating "Laugh for a Cure" and supporting research and clinical trials for Metastatic Breast Cancer coming to Canada. Having felt lost at the time of diagnosis, Tabitha knows how important community and connection are for those facing MBC. Tabitha enjoys being active, art, socializing, and travelling.