

## CADTH Reimbursement Review

# Patient Input

**AZACITIDINE (Onureg)**  
**(Celgene Inc., a Bristol-Myers Squibb Company)**

**Indication:** Acute myeloid leukemia

**CADTH received patient input from:**  
The Leukemia & Lymphoma Society of Canada

**March 26, 2021**

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CADTH does use reasonable care to prevent disclosure of personal information in posted material; however, it is ultimately the submitter's responsibility to ensure no personal information is included in the submission. The name of the submitting patient group and all conflict of interest information are included in the posted patient group submission; however, the name of the author, including the name of an individual patient or caregiver submitting the patient input, are not posted.

## CADTH Drug Reimbursement Review Patient Input Template

Name of the Drug and Indication	Onureg for acute myeloid leukemia
Name of the Patient Group	The Leukemia & Lymphoma Society of Canada
Author of the Submission	██████████
Name of the Primary Contact for This Submission	██████████
Email	████████████████████
Telephone Number	██████████

### 1. About Your Patient Group

#### The Leukemia and Lymphoma Society of Canada (LLSC)

The mission of LLSC is: Cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of Canadians affected by all of the 137 different types of blood cancer.

<http://www.bloodcancers.ca>

### 2. Information Gathering

Information was gathered through an on-line survey that was created by LLSC. The survey was created in both English and French, was made available to respondents on December 7, 2020 and closed on January 24, 2021.

Both English and French online surveys were created using Survey Monkey and promoted by LLSC through various social media channels and directly by email. The survey asked for input from those with experiences with the treatments for AML.

There were a total of 29 respondents to the survey. All of the respondents indicated that they were patients (persons with AML). No respondents indicated that they have taken Onureg.

18 respondents identified as Female, 10 respondents identified as Male, and 1 respondent did not provide a gender.

All respondents identified that they live in Canada. The breakdown is as follows:

Ontario - 13

Quebec - 6

British Columbia - 6

Alberta - 4

The age range of the patients are as follows:

25-34 - 3

35-44 - 3

45-54 - 3

55-64 - 9

65-74 - 9

75-84 - 2

28 of the respondents provided the year that they were diagnosed with AML:

2021 – 1

2020 – 4

2019 – 7

2018 – 5

2017 – 5

2016 – 3

2015 – 2

2014 – 1

### 3. Disease Experience

When asked how AML symptoms affected their daily lives, responses varied from being unable to exercise, being unable to work, impacting their social lives and relationships, and causing a number of detrimental effects on their health. Patients reported being easily fatigued, losing vision in one eye, nausea, bruising, numbness or body aches, and being immunocompromised. Many of these symptoms left them feeling physically and/or socially isolated and in fear of relapse leading to negative impacts on their psychological well-being.

The following quotes illustrate patients' experiences of living with AML:

- "I no longer do many of the active activities I did before the AML like hiking and biking. I was also forced into early retirement. My dating life is over. I still tire easily."
- "Very straining on relationships. Difficult to make plans and look to the future."
- "Can't return to work due to still being immunosuppressed post-stem cell transplant..."
- "The initial year was absolutely overwhelming, in terms of treatment and expenses."
- "Everything in my life stopped cold turkey-employment, social life, relationships, etc. I made a complete personal 360 degree pivot to focus on my healing and living."

- “Well COVID and my compromised immune system has caused me to be very socially isolated. I haven’t seen some very important people in my life for almost 2 years at this point.”

Interestingly, three respondents indicated exercise and physical activity helped with their fatigue and other symptoms, “I think all of the symptoms are difficult, to be honest, but perhaps for me the easiest over time was recovering my energy. I used exercise.”

AML affects not just those who are diagnosed, but also their caregivers. According to the survey, patients reported that caregivers or family members might feel stress, worry, sadness, insecurity, and fear of dying and expressed more tolerance towards the patients. Their companion through the disease journey was important for patients. One individual responded, “It affects those in your immediate household since they will most probably be your primary caregivers. However, anyone that is close to you will be affected as well.” Another added, “there is an element of fear for me and my family that it will return”. On the other hand, patients also described the support they received during their treatment and recovery, and one individual reflected, “they worked hard to support me, visit me in hospital, take me to appointments, arrange food, etc.”

#### 4. Experiences With Currently Available Treatments

According to the survey, the frontline treatment that patients received after diagnosis included chemotherapy (n = 24), stem cell transplant / bone marrow transplant (n = 16), drug therapy (n = 6), radiation therapy (n = 5), and chimeric antigen receptor (CAR) T-cell therapy (n = 1). The side effects caused large impact on patients’ quality of life and included hair loss (n = 17), weakness (n = 15), extreme fatigue (n = 14), diarrhea (n = 10), infections (n = 8), anemia (n = 8), mouth sores (n = 8), nausea and vomiting (n = 7), fever (n = 6), low blood cell counts (n = 6), tingling sensations (n = 4), constipation (n = 2), graft-versus-host disease (n = 2), lung, heart, kidney or nerve problems (n = 2), cough (n = 1), rashes (n = 1), shortness of breath (n = 1), and psychological distress (n = 1). The side effects due to chemotherapy and stem cell transplant had large impact on patients’ quality of life. These side effects led to changes in physical activity (n = 15), anxiety (n = 11), problems in mental health and overall happiness (n = 11), eating challenges (n = 12), social development (n = 6), and educational development (n = 6). Some of the side effects caused significant disturbance to daily living. Feelings of isolation, for instance, during hospitalization for stem cell transplants, was another common issue among respondents. Opportunistic infection could occur. Below are comments from patients regarding their experiences with AML treatments:

- The main challenge was the nausea and vomiting. I didn’t seem to have much control over it and had my wonderful bucket always with me. I could be fast asleep and awake and vomit.
- Your whole world changes when you are diagnosed with AML. Suddenly, you confront your mortality. You feel extremely weak, you have to go into hospital for months, and you don't realize you MUST go into remission to have a stem cell transplant.
- “The Chemo, transplant, radiation and drug therapies are all hard on the body and short term, long term effects are tough as well. The worst part is that these therapies can cause other illnesses.”

- “The most difficult experiences I had involved the stem cell transplant and the intensive chemotherapy. I became very ill and was hospitalized for several weeks. I would say that the other difficult experience was being diagnosed with AML and told I had one month to live, without treatment. I had hardly any symptoms and was absolutely shocked. We had to move to another city for treatment, as well.”

Patients that responded to the survey reported a mixture of both positive and negative experiences accessing treatments. Thirteen respondents reported generally positive experiences and some patients attributed to the support from medical staff. Six patients reported negative experiences. Negative experiences were due to a long referral period with their physician, lack of treatment information, difficulty getting a room for consolidation therapy, having to receive treatment in another city or province, being away from their support system as a result of moving, and the general lack of psychological support.

## 5. Improved Outcomes

The majority of respondents to the survey indicated that the factors they considered about a new cancer treatment were physician recommendation (n = 19), possible impact on disease (n = 17), quality of life (n = 12), closeness of home (n = 9), and outpatient treatment (n = 8).

The survey patient respondents also reported the characteristics of new treatment options that they hoped to have, particularly, maintaining remission, having fewer side effects, costing little, and being assessable in their neighborhoods. Other supportive options, such as meditation, hypnosis, neuro-linguistic programming support, and awareness support (thoughts, emotions, and behaviors), were mentioned.

## 6. Experience With Drug Under Review

No survey respondents indicated that they have taken Onureg.

## 7. Companion Diagnostic Test

N/A

## 8. Anything Else?

Is there anything else specifically related to this drug review that CADTH reviewers or the expert committee should know?

## Appendix: Patient Group Conflict of Interest Declaration

To maintain the objectivity and credibility of the CADTH drug 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 two years AND who may have direct or indirect interest in the drug under review.

Company	Check Appropriate Dollar Range			
	\$0 to 5,000	\$5,001 to 10,000	\$10,001 to 50,000	In Excess of \$50,000
Bristol-Myers Squibb				X
Celgene				X

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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: Indrek Koppel

Position: Manager, Advocacy & Partnerships

Patient Group: The Leukemia & Lymphoma Society of Canada (LLSC)

Date: March 26, 2020