

## CADTH Reimbursement Review

# Patient Input

**RISPERIDONE (Perseris)**  
HLS Therapeutics Inc.

**Indication:** Schizophrenia, adults

**CADTH received patient input from:**  
Institute for Advancements in Mental Health

**February 22, 2021**

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CADTH does not edit the content of the submissions.

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 Reimbursement Review Patient Input Template

Name of the Drug and Indication	Risperidone (Perseris), Schizophrenia, adults
Name of the Patient Group	Adults with psychotic illness; Institute for Advancements in Mental Health (formerly the Schizophrenia Society of Ontario)
Author of the Submission	Institute for Advancements in Mental Health
Name of the Primary Contact for This Submission	██████████
Email	████████████████████
Telephone Number	██████████████████

### 1. About Your Patient Group

Describe the purpose of your organization. Include a link to your website.

The Institute for Advancements in Mental Health is a connector, collaborator, thought leader and solution driven organization; supporting, innovating and driving change for better mental health. IAM innovates in mental health with a focus on returning solutions back to communities, through partnership and collaboration. Historically serving those impacted by psychotic illnesses such as schizophrenia and psychosis, IAM serves anyone impacted by serious mental illness and their families, caregivers/supports and communities. Our direct services include one-on-one and group counselling utilizing cognitive behavioural therapy-based interventions, information and system navigation, training for frontline workers, community education and more.

Website: <https://www.iamentalhealth.ca/>

### 2. Information Gathering

*CADTH is interested in hearing from a wide range of patients and caregivers in this patient input submission. Describe how you gathered the perspectives: for example, by interviews, focus groups, or survey; personal experience; or a combination of these. Where possible, include **when** the data were gathered; if data were gathered **in Canada** or elsewhere; demographics of the respondents; and **how many** patients, caregivers, and individuals with experience with the drug in review contributed insights. We will use this background to better understand the context of the perspectives shared.*

This submission is based on our 40 year history of serving adults with schizophrenia and other psychotic illnesses, their families, service providers and communities. Much of our learning has

come directly from our work with clients and the expertise of our frontline staff. We also draw on knowledge gained from a survey of our client network which was conducted by IPSOS in 2018.

Our clients are primarily adults from the southern and central regions of Ontario though we do serve a number of clients virtually from northern regions of Ontario. They comprise individuals who experience symptoms of schizophrenia or psychosis (not all of our clients have a diagnosis), as well as the family members, friends and community members who interact with those individuals. Our clients also include health service providers and social service providers who work with individuals with psychotic illnesses, including schizophrenia.

Clients and survey respondents range in age, gender, educational background, income and employment status.

Within the IPSOS survey, respondents self-described as:

12% “personally diagnosed”

50% “caregiver”

63% “family member/friend of someone diagnosed”

18% “work in social services”

77% of survey respondents were born in Canada with 83% self-describing as “white.” 55% of respondents came from the GTA, while 20% came from southwestern Ontario, 14% came from Eastern Ontario, 5% from Central Ontario and 4% from Northern Ontario. An additional 2% came from outside Ontario.

### 3. Disease Experience

*CADTH involves clinical experts in every review to explain disease progression and treatment goals. Here we are interested in understanding the illness from a patient’s perspective. Describe how the disease impacts patients’ and caregivers’ day-to-day life and quality of life. Are there any aspects of the illness that are more important to control than others?*

Our patient group includes individuals with schizophrenia and other related illnesses with psychosis as a main feature. Many of our clients experience symptoms of psychosis without having a formal diagnosis. Oftentimes, their symptoms have a significant impact on day-to-day functioning. Our clients experiences vary widely but typically involve some levels of cognitive impairment, delusions and hallucinations. The cognitive impairment can range from mild to severe but is typically strongest in the cognitive domains of working and episodic memory, attention, processing speed, problem-solving and social cognition. A large number of clients also experience anosognosia, a lack of insight into their illness, which often impacts their ability and motivation to access treatment and supports. This symptom can cause significant strain in relationships, including those with caregivers and family members, ultimately leading to social isolation and a lack of supports for the individual with the illness.

## 4. Experiences With Currently Available Treatments

*CADTH examines the clinical benefit and cost-effectiveness of new drugs compared with currently available treatments. We can use this information to evaluate how well the drug under review might address gaps if current therapies fall short for patients and caregivers.*

*Describe how well patients and caregivers are managing their illnesses with currently available treatments (please specify treatments). Consider benefits seen, and side effects experienced and their management. Also consider any difficulties accessing treatment (cost, travel to clinic, time off work) and receiving treatment (swallowing pills, infusion lines).*

In our 2018 study of our network, 55% of respondents were taking long acting injectable medications or had taken them before, while 98% were taking or had taken oral medications to manage their schizophrenia/psychosis symptoms. The most common side-effects they reported were drowsiness (58%), dry mouth (50%), restlessness (50%), dizziness (45%), muscle stiffness (45%), constipation (43%) and anxiety (43%).

Of those taking long acting injectable medications, the most common stated benefits were convenience and not needing to remember to take it every day. The difficulties were most frequently stated to be pain at the injection site and frequent travel to clinics.

While 63% of our respondents paid for their medications with government insurance, 23% paid out of pocket for their medications.

23% of respondents identified the cost of medications as a significant challenge to access. Other challenges identified included: preferred medication not being covered by public drug programs (20%), and wait times for approvals of certain medications under the Ontario Public Drug Program Special Access Programs and Exceptional Access Programs (13%).

63% of respondents agreed that it is difficult to pay for health care bills including medication, visits to specialists, counselling, etc.

## 5. Improved Outcomes

*CADTH is interested in patients' views on what outcomes we should consider when evaluating new therapies. What improvements would patients and caregivers like to see in a new treatment that is not achieved in currently available treatments? How might daily life and quality of life for patients, caregivers, and families be different if the new treatment provided those desired improvements? What trade-offs do patients, families, and caregivers consider when choosing therapy?*

For our patient group, treatment and recovery is a nonlinear, individual process. For many, the process of finding the right medication that allows for the highest level of daily functioning, while managing side-effects, is often achieved through a “trial and error” process of trying several different medications and dosages to find what works best. This process can make it difficult for clients to adhere to treatment and is exacerbated by additional challenges such as difficulty accessing psychiatrists, obtaining prescriptions, understanding medication options, cost of medications, and wait times to access medications through public drug programs. When the right combination of therapy and medication is determined, individuals may still experience relapse and may require extensive supports to adhere to the treatment plan.

This “trial and error” practice of finding the right medication for each individual would be improved by having quick, simple and affordable access to a wide range of treatments and medications to suit unique needs.

## 6. Experience With Drug Under Review

*CADTH will carefully review the relevant scientific literature and clinical studies. We would like to hear from patients about their individual experiences with the new drug. This can help reviewers better understand how the drug under review meets the needs and preferences of patients, caregivers, and families.*

*How did patients have access to the drug under review (for example, clinical trials, private insurance)? Compared to any previous therapies patients have used, what were the benefits experienced? What were the disadvantages? How did the benefits and disadvantages impact the lives of patients, caregivers, and families? Consider side effects and if they were tolerated or how they were managed. Was the drug easier to use than previous therapies? If so, how? Are there subgroups of patients within this disease state for whom this drug is particularly helpful? In what ways? If applicable, please provide the sequencing of therapies that patients would have used prior to and after in relation to the new drug under review. Please also include a summary statement of the key values that are important to patients and caregivers with respect to the drug under review.*

We do not have knowledge of our clients use of Perseris (risperidone).

## 7. Companion Diagnostic Test

*If the drug in review has a companion diagnostic, please comment. Companion diagnostics are laboratory tests that provide information essential for the safe and effective use of particular therapeutic drugs. They work by detecting specific biomarkers that predict more favourable responses to certain drugs. In practice, companion diagnostics can identify patients who are likely to benefit or experience harms from particular therapies, or monitor clinical responses to optimally guide treatment adjustments.*

*What are patient and caregiver experiences with the biomarker testing (companion diagnostic) associated with regarding the drug under review?*

*Consider:*

- *Access to testing: for example, proximity to testing facility, availability of appointment.*
- *Testing: for example, how was the test done? Did testing delay the treatment from beginning? Were there any adverse effects associated with testing?*
- *Cost of testing: Who paid for testing? If the cost was out of pocket, what was the impact of having to pay? Were there travel costs involved?*
- *How patients and caregivers feel about testing: for example, understanding why the test happened, coping with anxiety while waiting for the test result, uncertainty about making a decision given the test result.*

We are unable to provide this information for our patient group.

## 8. Anything Else?

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

The greater the variety and affordability of medications on the market, the more treatment adherence we are likely to see among individuals with schizophrenia and psychosis, and by extension, greater levels of recovery. IAM advocates for a wide selection of reimbursable medications in the Canadian marketplace.

## 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.

This submission is partially informed by data previously gathered by IPSOS Public Affairs for a 2018 survey of our network. The purpose of the survey was to: better understand the perceptions of our organization; assess the familiarity, use, and helpfulness of our services; determine what advocacy issues to focus on; and to understand the experience of those personally diagnosed with schizophrenia or psychosis and their caregivers, including their rating of access and wait times for various services or treatments, and the financial burden of living with schizophrenia or psychosis.

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
HLS		X		
Janssen				X
Otsuka				X
Sunovian	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: Kaelen Boyd

Position: Policy and Government Relations Lead

Patient Group: Adults with psychotic illness [Institute for Advancements in Mental Health (formerly, Schizophrenia Society of Ontario)]

Date: February 22, 2021