Canadian Blood Services' Patient Engagement Forum

Fall 2022 meetings summary report

Introduction and Background

In the spring of 2022, Canadian Blood Services launched an important new stakeholder engagement body, the Patient Engagement Forum.

The development of the Forum was based on an understanding that Canadian Blood Services could be engaging patient organizations more frequently, more inclusively and in more robust ways. Such input helps CBS to better appreciate what stakeholders are hearing from patients, what issues and concerns are emerging, and what we could be doing differently to best meet patient needs.

After a successful first round of meetings in the spring of 2022, the membership came back together for its second set of meetings in November and December 2022. Like the previous set of meetings, the agendas and topics for discussion were determined through discussions and outreach to participant organizations directly, and via the Engage+ portal.

Forum meetings took place on:

- Plasma community: November 17
- Stem Cells community: November 28
- Blood community: December 5
- Joint session: December 13

What follows are brief summaries from each of those meetings, associated action items, and next steps.

Meeting Summaries

Plasma community: November 17

Based on discussions with members, the meeting's agenda focused on the Canadian Blood Services' blueprint to increase plasma collection and on Formulary management. There was also a structured roundtable where patient groups could bring potential product issues to our attention.

Throughout the meeting, participants expressed considerable support for our steps to increase the supply of immunoglobulins (Ig) collected in Canada, especially for our contract with Grifols. Many have been following developments closely and there were questions about what Grifols'

operations might look like in the future, including whether they would be permitted to open centres in Ontario and British Columbia as an agent of Canadian Blood Services.

Participant organizations shared some of the steps they have taken to try to frame media coverage of the Grifols contract on patients and what a more secure domestic supply chain of plasma products means for them. Throughout the discussion, there was recognition of the importance of that voice, and a willingness to continue working together to ensure that perspective is present in media stories, and with funding governments.

Roundtable issues:

- GBS/CIDP expressed a potential concern about reports that more patients with the condition are having their immunoglobulin dosing based on an ideal body weight for their gender and age, rather than their personal weight per product monograph. There are no definitive studies or results at present to determine if this is impacting patient outcomes. While utilization and dosing do not fall under the CBS mandate, these developments are important to be aware of.
- Several groups had questions about the PPRP product selection process and decision to end the brand review. They expressed concerns that this may impact patient access to new and/or innovative therapies. Earlier this year, provincial and territorial governments approved our recommendation to simplify how products are added to the PPRP Formulary by removing the brand review process. This was communicated to patient stakeholders at that time. Some patient groups raised questions about the timelines for reviewing new or innovative products, which Dr. Sylvain Grenier, the Director of the PPRP Formulary, addressed. We understand that several patient organizations still have frustrations with the product review processes, despite the assurances provided by staff that a pathway exists to assess new therapies and introduce them to the Formulary if they provide a clear clinical benefit to patents if it is financially sustainable to do so.
- The Canadian Association for Porphyria shared a concern, based on a personal experience, about hospital staff awareness and familiarity with how to order and access product for patients in urgent need. Canadian Blood Services is following-up on this issue.

Stem Cells Community meeting: November 28

The Stem Cells community meeting began with an in-depth discussion of a new tool Canadian Blood Services is about to launch designed to helps patients and their families launch recruitment campaigns and inspire potential donors to join the stem cell registry.

Rachel Bezaire, marketing specialist at Canadian Blood Services, gave Forum members a live demonstration of the new online tool and asked the patient groups for their feedback on

potential improvements and ways stakeholders can help promote the tool to patients and families in the stem cell community once it has been launched.

- The online tool was well-received by members, with many expressing interest in using and sharing it with patients and families. Staff agreed to follow up with several patient groups to explore further ways to work together to put the tool to good use.

Forum remembers also heard from a few participant organizations (Leukemia and Lymphoma Society of Canada and the Sickle Cell Awareness Group of Ontario) about the work they are doing to better engage diverse communities.

These presentations led into a structured round table discussion where participant organizations shared some of their experiences and insights gained over the last several months.

Several clear themes emerged from that session:

- Clear, concise, and easy to find information remains a critical gap for many patients needing to undergo a transplant. Participant organizations highlighted these particular challenges during discussion and shared some of the initiatives they have undertaken to meet the need. There were opportunities identified for collaboration between Canadian Blood Services and patient organizations that will be followed up on.
- Concerted efforts to engage diverse communities is required and critically important. Tailored information and outreach is needed, one approach will not work for all.
- The pandemic increased isolation for vulnerable communities though it also presented opportunities for pre-existing health compromised individuals to share their best practices for engaging with patients and families virtually. Many organizations acknowledged that virtual ways of reaching patients and families will continue into the future but are hoping to find a better balance of in-person and remote support activities.

Blood Community meeting: December 5

The Blood community meeting featured an early preview of some work underway around malaria deferrals, and a planned risk-based decision-making process on the issue that will take place next year.

Many participants in this meeting will ultimately take part in that process so this was an opportunity for them to explore some of the very early thinking about the structure of those discussions, and the important voices that will need to be a part of the work.

Forum member Lanre Tunji-Ajayi shared some detailed information about the work her group, the Sickle Cell Awareness Group of Ontario, has undertaken in recent months, and Dr. Jennie Haw, along with Biba Tinga of the Sickle Cell Disease Association of Canada, returned to follow-up on their presentation at the spring meeting. They shared an update and results from their

collaborative research project that examined barriers and enablers to blood donation in the black community.

A number of participants expressed interest in connecting with the presenters to explore their ideas and insights further. The stakeholder engagement team will follow up on those requests.

Joint meeting: December 13

The joint session of the Patient Engagement Forum was built around a discussion about gene therapies. This session was designed to explore member organizations' views on gene therapies, gauge their knowledge and interest in these potential treatments, and help inform CBS' early thinking on what role it could or should play in the space.

It was clear through discussion that there are varying levels of interest and awareness on this issue, with some very clearly seized of the matter, and others that are just starting to learn about the potential implications.

Key findings from the consultation include:

- **These therapies are not necessarily seen as "cures":** While there is excitement about the potential impact of gene therapies, it was noted in particular by the Canadian Hemophilia Society (CHS), that there is a growing realization that these therapies are not currently curative and that there are best understood as short to medium-term "breaks from treatment" rather than permanent cures.

- **At this stage, only small numbers of patients may benefit from gene therapy:** It was noted that gene therapies are not available for pediatric patients, even though it seems to offer the most impact in terms of quality of life for those patients. Even within the relatively large hemophilia community, CHS estimated that only small numbers of patients would benefit from these therapies; perhaps only 50 people.

- **Product trials, approvals and licensure will require creativity:** ImmUnity Canada (formerly the Canadian Immunodeficiencies Patient Organization) noted that some pharmaceutical corporations have released and ceded the control and development work for some of their therapies to academic institutions. They asked how this would impact the PPRP CBS-CADTH process, which is driven by vendors, not currently other institutions. HAE Canada noted that while there is awareness of a potential HAE gene therapy being looked at, when the time comes, it may be difficult to populate a trial because patients are required to stop existing treatments to participate, introducing risk to the management of their condition.

- **Delivery of treatment and follow-up is very important and will be challenging:** There is much interest in how products will be delivered, and equally importantly, how patients will be monitored in the critical six-month period following treatment. CHS suggested a Centres of Excellence model, because the number of treaters with the qualifications to deliver these therapies is low, and they tend to be located in larger centres. However, this centralized model may introduce risk in terms of equity and accessibility of treatment for patients.

- **Data collection and tracking must be robust:** Stakeholders recognize that there is uncertainty about the long-term safety and effectiveness of gene therapies, so being able to track and monitor the positive and negative outcomes for patients is extremely important

- **Reimbursement models will be important and will need to be reconsidered:** Many patient groups, indicated that reimbursement and formulary management are top of mind issues, and there are diverging opinions about how best to handle this issue. The Network of Rare Blood Disorder Organizations (NRBDO) indicated this is the primary issue they are grappling with, including about how to make treatments available without bankrupting formularies (especially if the model involves high upfront as opposed to recurring costs). Some patient groups, including, CHS shared its belief that these products belong under the CBS umbrella, as there is logic in keeping hematological products together in one formulary. In contract, the Canadian Organization for Rare Diseases (CORD) had a different perspective and made the case that these therapies more properly fit within the rare diseases drug strategy that has been under discussion with the Government of Canada.

- **Managing patient and treater expectations is important:** Expectations among patients and even in physician communities are high in the community, and with each new therapy that is approved and talked about in media, expectations will continue to grow. Patient groups said they understand that many of these therapies will not necessarily live up to the hype or be as effective as hoped. As a result, some groups identified education is being important here, and a role that patient groups could potentially play in educating individual patients and physicians.

We commit to updating forum members on the development of a Canadian Blood Services perspective on gene therapy when appropriate, as it develops and evolves.

Evaluation

Immediately after the joint session, all participants received an evaluation survey to share feedback and input on the fall meetings.

> *"A bit of background before discussions would sometimes be helpful"*

Responses indicated a generally high-level of satisfaction with the Forum, as well as some helpful suggestions for continued refinement. In summary, here is what was heard:

> *"It's nice to have the ability to provide feedback and discuss issues in a group setting"*

What's working well:

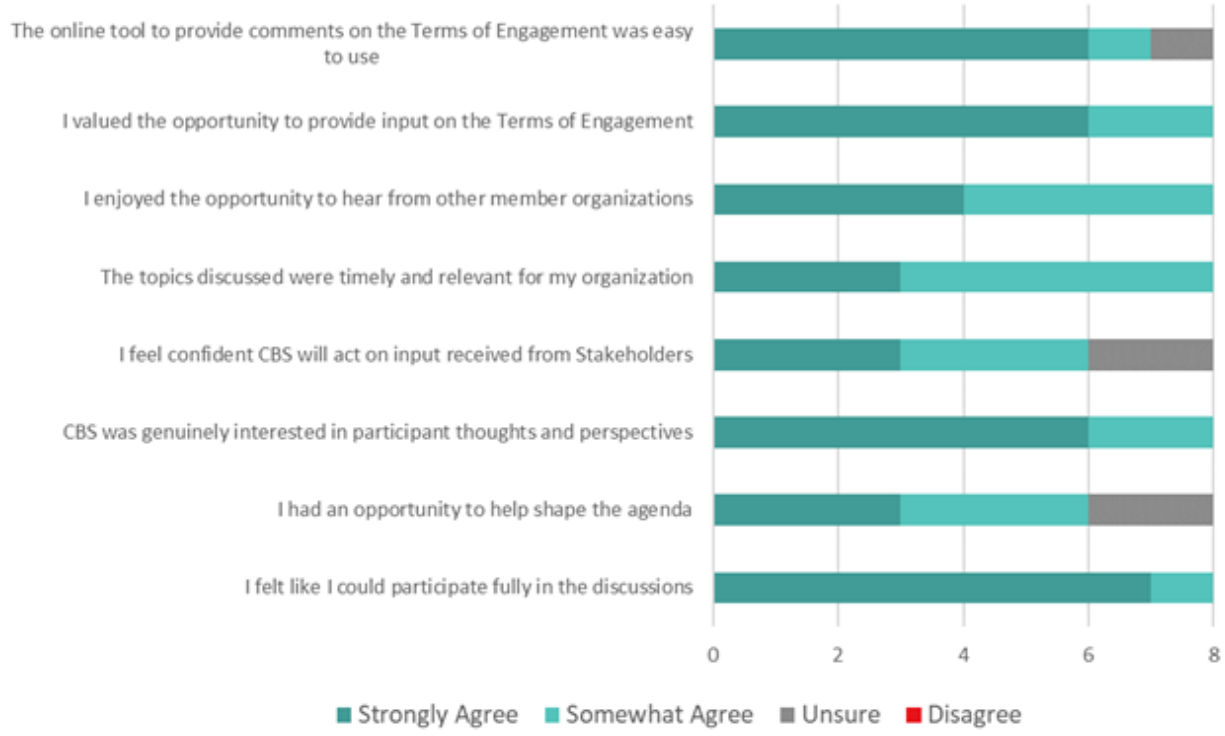
- Good variety of stakeholder and patient perspectives represented
- Opportunity to connect with and learn from the experiences of other groups
- Timely, appropriate topics on the agenda and truly open discussions around them

Ideas for improvement:

- Longer lead time in setting dates and agendas
- Background or level-setting information before the meetings would be helpful

> "*Scheduling further in advance*"

Data from closed-ended questions:



Next Steps

Now that the Fall cycle of meetings has concluded, Canadian Blood Services will be following up on action items and reflecting on the evaluation results to ensure the Forum continues to evolve in a way that increases its value to members and to CBS.

As noted in the joint meeting, in February, we will be inviting all members to an online engagement process built to solicit feedback and input on Canadian Blood Services' draft Stakeholder Promise.

The next round of meetings will take place in the spring of 2023. Invitations and calls for agenda items will be sent well in advance.

Appendix A – Action items

Here is a list of action items we have captured and which we will keep you updated on.

Action item	Status
Investigating experiences where patients have had difficulty accessing Panhematin in urgent situations	Stakeholder Engagement team is soliciting advice from the CBS hospital liaison team for how best to address the issue. Will connect back with the Canadian Association for Porphyria early in the new year
Access to solvent detergent plasma for TTP patients	Stakeholder engagement team is drafting a communications piece for Answering TTP that outlines the upcoming move to S/D Plasma along with timelines.
Share Stem Cells patient resources and support pages when officially launched	Complete
SCAGO would like to connect its marketing people with Rachel's team to go through the stem cell tools and explore ways to share further into the community	Initial meeting took place January 24
CBS Stem cell team members requested to speak to Leukemia & Lymphoma Society community service leads	Complete. Kathy Ganz and Dr. Matthew Seftel spoke to the group at their meeting on January 11.