

Canadian Blood Services' Patient Engagement Forum

Spring 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. We need 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.

Unlike previous stakeholder committees, the Forum is designed to bring together a very broad cross-section of patient organizations, which will better provide the organization with perspectives and first-hand insights and feedback on issues of importance to those that use the products and services facilitated by Canadian Blood Services.

The design of the Forum was done collaboratively, with a wealth of input from participant organizations, and follow-up surveys and conversations in the weeks following the spring meetings will help further refine the structure and operations of the Forum.

The Forum officially launched on April 28, with a meeting of the full membership, followed by the individual “community” meetings:

- Blood community: May 3
- Stem Cells community: May 10
- Plasma community: May 18

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

Meeting Summaries

Joint Session: April 28

The first ever Forum meeting began with welcoming remarks from Canadian Blood Services' VP Public Affairs Ron Vezina, and Board of Directors Consumer Representatives David Lehberg and Bob Adkins.

Canadian Blood Services' CEO, Dr. Graham Sher, then presented a detailed overview of the organization's performance and areas of focus over the past years. Members then had the opportunity to engage in a question-and-answer session.



The discussion covered a range of topics including the current donation interval for individuals with hemochromatosis, and the feasibility of altering it; the plan to increase Canadian sufficiency in plasma and the dedicated centres which have been opening, as well as a discussion about the possibility of domestic fractionation in Canada; questions around Canadian Blood Services' successful regulatory submission to Health Canada asking to remove criteria specific to men who have sex with men, and about protocols to ensure system safety; and about the likelihood of someday having access to synthetic red blood cells for transfusion.

In several cases, Canadian Blood Services committed to sending additional information to questioners via email following the meeting.

Next, Dr. Chantale Pambrun and Dr. Kelly Holloway spoke about Canadian Blood Services' research program, and the opportunities for patients to participate in those projects. Members then took a closer look at Dr. Holloway's current research project focused on collecting the lived experience of IG recipients and understanding theirs, as well as clinician, knowledge and perceptions about the processes that determine product availability.

Recruitment for the project will begin in June, and Dr. Holloway committed to following-up with the Forum members that expressed interest in potentially participating.

Finally, Danielle Leguard-White and Beth Frise provided an overview of the Partners for Life donor recruitment program.

Several participants expressed interest in learning more, and Danielle and Beth have been connecting with those individuals to talk more about the program and registration.

Blood Community meeting: May 3

The Blood community held its first meeting on May 3. The agenda was designed to reflect topics of interest to participants, and included items suggested by the members.

Dr. Mindy Goldman led an overview of donor eligibility screening, and how criteria are added, changed, or removed as scientific and technological developments allow.

This led into a very specific discussion with Dr. Chantale Pambrun about the sexual-behaviour based screening which will be implemented this fall.

Participants discussed the deferral criteria for malaria and other diseases, as well as donation interval criteria.

Dr. Jennie Haw, and Ms. Biba Tinga of the Sickle Cell Disease Association of Canada, then presented a research project they are collaborating on that examines barriers and enablers to blood donation in the black community.

The membership had a robust discussion about the specific project in question, about some early learnings and what they hope to learn as the project moves on.

There was a strong desire to hear an update at the fall meeting, and several other groups expressed interest in learning more, or in helping identify and scope similar research in other communities.

The stakeholder engagement team is helping facilitate those ongoing conversations.

Stem Cells Community meeting: May 10

The Stem Cells community held its first meeting on May 10. More so than the Blood and Plasma communities, the Stem Cell community features a number of relatively new stakeholders for Canadian Blood Services. Given that, the early part of the meeting was devoted to an overview of the Stem Cell registries (adult and cord blood) and the broader network that the organization participates in.

Kathy Ganz, Director, Stem Cells, lead that detailed overview and then answered questions about the key areas of focus for the program, including diversity and the work underway to better ensure the registry reflects the Canadian population.

Dr. Tanya Petraszko then led an interactive discussion focused on what patients experience on their road to transplantation. The discussion focused on three key questions:

- How are the patients you and your group represent accessing transplants?
 - What are they experiencing on their road to transplantation?
- Are there challenges that exist?
 - At a health systems level and/or at a patient level?
- Ways we can work together to identify barriers and potential solutions

The discussion identified a few key themes:

- The need for resources to help patients and families understand the process, what to expect before, during and after transplant. That would include knowing some of the milestones and some of the potential complications to look out for following the procedure.
- Supports for patients and caregivers. A way to find groups and support organizations in specific regions that can help families going through the process. There is a lot of fear for many people knowing they need this procedure and it can be difficult to find answers or connections with others that have experienced this.
- There are financial burdens for many families, especially those that live outside of larger cities with transplant centres. It often requires patients and caregivers to relocate for treatment, sometimes for long durations, and that takes a financial and a mental toll.
- Systemic issues in accessing health care providers to get diagnosed or referrals



- There are concerns for patients that are not of Caucasian ancestry, will they be able to find a match at all, let alone within the necessary time frames. There is a need to work with communities to identify eligible donors and develop strategies to effectively recruit to the registry.

Stakeholder engagement has reached out to the members that were not able to take part in the discussion to ensure their voices are captured in this important conversation.

Plasma Community meeting: May 18

The Plasma community held its first meeting on May 18. Like the previous community meetings, the agenda was largely defined by issues and topics of interest that were raised or proposed by members.

The meeting focused on two main topics of discussion:

- What is being done to increase domestic plasma sufficiency
- How does CBS manage the formulary of Plasma Protein and Related Products (PPRP) including the various product review processes as well as the RFP product procurement process

Elizabeth Stucker, Director, Strategic Planning and Integration, led the discussion about work underway to increase collections of source plasma, and the strategic plan to reach the target sufficiency level of 50%.

A wide-ranging discussion that included questions about recruitment and whether mobile plasma collection events would be possible on post-secondary campuses, the long-term strategy as it relates to the non-remunerated voluntary system, and the milestones between 25 and 50% sufficiency, took place.

Then, Dr. Sylvain Grenier, Director PPRP Formulary, engaged the group in discussion about formulary management in the context of product review processes and the RFP model for procurement.

The conversation touched on the ways pricing is calculated and factored into negotiations; how patient perspectives are brought into the review process, and at what times those patient voices are sought; the role of CADTH and how its work intersects with the work that CBS does, and how the two phases of a product review align; there was a discussion about how the organization acquires SD (solvent detergent) plasma for patients; and a discussion about the principle of equity in the system.

Next Steps

Now that the spring cycle of meetings has concluded, Canadian Blood Services will be following up on action items, and ensuring any additional questions posed online or via email after the events are answered.



We will also be reflecting on this round of meetings and identifying areas that worked well, or that could use a different approach or some refinement. A survey was sent to all participants to gauge their views on those topics as well. Over the next few months, the Stakeholder team may reach out to various participants as well to ask some additional questions.

The next round of meetings will take place in the Fall, likely in the late October/early November timeframe. Invitations and calls for agenda items will be sent several months in advance.