



Canadian Blood Services' Patient Engagement Forum

Spring 2023 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 and fall of 2022, the membership came back together in May 2023.

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: May 10
- Stem Cells community: May 15
- Blood community: May 25
- Joint session: May 29

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

Meeting Summaries

Plasma community: May 10

Based on discussions with members, the meeting's agenda focused on the Canadian Blood Services' blueprint to increase plasma collection and on Formulary management including reflections on the evolution of the Request for Proposals (RFP) process. There was also a member profile focused on the Platelet Disorder Support Association, as well as a structured roundtable where patient groups could raise issues of concern, or share insights and feedback from members of their communities.



Throughout the meeting, participants expressed strong support for Canadian Blood Services' strategy to increase the supply of plasma collected in Canada. Many have been following developments closely and there were questions about what Grifols' operations might look like moving forward, and what the next steps are in that process.

Members talked about the mechanisms in place to help ensure there is no impact on whole blood and other collections throughout the country, and expressed interest in knowing where and when Grifols will start opening centres and contributing finished product to the Canadian supply.

Dr. Sylvain Grenier then led a session reflecting on the continuing evolution of the RFP process that Canadian Blood Services uses to manage the therapies available through its PPRP formulary.

Members who have participated in the RFP process indicated that the changes enacted over the last few years have led to improved visibility and transparency in the process, and to good outcomes for patients.

It was shared that background information and training on the process is valuable, and that the clarity around time commitments and expectations was appreciated.

A request was made for the development of a communications vehicle that would help participants socialize the work that goes into the RFP process and how decisions are ultimately reached. There was a thought that this would help participant organizations identify the best people to put forward in the process and allow them to come to the table more fully prepared. We will follow up on this request.

Jennifer DiRaimo, Research Program Manager with the Platelet Disorder Support Association (PDSA) spent a few minutes providing a very well-received overview of platelet disorders, the available treatments, and the work the PDSA does on support of patients across Canada. Members thanked Jennifer for the presentation and introduction to the PDSA's important work for patients and their families.

To close the session, we held a participant roundtable.

Roundtable issues:

- ImmUnity Canada shared their experiences from recently hosting their first in-person conference since the pandemic began, and about the positive feedback received from participants. They also shared that they are starting to hear some concerns from patients about plasma collections, particularly what the situation will be in British Columbia, and if there are things patients can do to ensure their voices are heard.
- Alpha-1 Canada spoke about the ongoing RFP they are involved with, and how it connects to the Interim Review Process. They also shared frustrations with the length of



time the process can take and a lack of clarity on timelines once matters go to the CDM and P/Ts. Patients are frustrated with this lack of visibility and clarity.

- The Canadian Hemophilia Society agreed that timelines around RFPs are important, and the more clarity that can be offered, the better. They also noted that gene therapy remains of interest to them and their members, but that a great deal of education is still required on the subject. They are hearing from members that there is a strong desire to return to in-person meetings and events, and that people are ready to get back to that sort of normalcy.
- Kawasaki Disease Canada shared that they are looking for some advice on building their network and connecting with other professional and industry bodies. Reps from the Canadian Hemophilia Society, and ImmUnity Canada offered to connect for discussions. The International Kawasaki Disease Symposium will be held in Montreal in 2024, the first time this conference will be hosted in Canada, and they would like to explore ways CBS can be involved in this.

Stem Cells Community meeting: May 15

In connecting with members of the Stem Cells community, participants indicated they'd like to get a deeper understanding of the patient journey from diagnosis to transplant, and about the various pieces that Canadian Blood Services is involved in, and the resources available to families and patients.

Chris van Doorn, Relationship Management Associate in our Stem Cells group, along with Medical Officer Dr. Matthew Seftel, provided a deep dive into the mechanics of the registry management, how searches are conducted both at home and through international registries, and how the various parts of the system interconnect and operate.

Chris also provided a look at the suite of tools that has been designed to help patients and their families launch recruitment campaigns of their own and inspire potential donors to join the stem cell registry.

There were questions and discussions about the shift from bone marrow to peripheral blood stem cells, and the instances where each collection is preferred and appropriate. There was also dialogue about registrant management, and what we do to ensure that those on the registry are willing to follow through on donation, how we ensure we can stay in contact with registrants, how long they stay on the registry

The team then spoke about a recent, very successful, recruiting event held in the Toronto area that featured a pop-up barbershop, and that generated tremendous media attention and a significant number of new registrants.



Kathy Ganz, Director of Stem Cells, then spoke about the current constitution of the Canadian Registry, and what we're doing on the recruiting front and the positive impacts we are seeing from a return to in-person events.

There was discussion about alignment with other international registries, and members asked about age criteria for various registries, as well as the shift away from young male donors to young donors in general.

The Leukemia and Lymphoma Society shared that they too are starting to return to in-person events and finding them to be well-received. There was some discussion about creative ways to spread the word about events by utilizing platforms like Tik Tok and posters at large public events like the Calgary Stampede.

LLS also indicated that they host a podcast channel focused on blood cancers, and that there could be a good opportunity to participate on a podcast and talk about the need for stem cells registrants and how the system works.

Blood Community meeting: May 25

The Blood community meeting featured presentations from Jen DiRaimo about the Platelet Disorder Support Association (a return by request after her presentation to the Plasma community) and from Lanre Tunji-Ajayi who shared details about a newly launched global initiative called the Global Action Network of Sickle Cell and Inherited Blood Disorders (GANSID).

Dr. Mindy Goldman, Medical Director, Donation Policy and Studies, then joined the group to talk about monitoring, evaluation, and ongoing evolutions of donor selection criteria at Canadian Blood Services.

Mindy shared some of the early data gathered since the implementation of sexual behaviour-based screening, and how there have been very low deferral rates related to the new criteria, and no increase in HIV rates. These results are similar to what has been seen in the UK.

She also shared information about two other criteria changes this year, the addition of criteria around mpox (formerly known as monkeypox), and the removal of specific travel criteria around COVID-19.

Work is underway looking at the criteria for prospective donors with certain forms of cancer (after curative treatment), and on the deferrals for those who resided in areas related to vCJD exposure.

Participants shared that Platelet Disorder awareness month will be held in September; that June 19th is World Sickle Cell Day; and that the Canadian Hemophilia Society will be releasing a patient story to help mark World Blood Donor Day.



Joint meeting: May 29

The joint session of the Patient Engagement Forum was built around two key pieces, an Ask me Anything with CEO Dr. Graham Sher, and a discussion about the organization's Diversity, Equity, and Inclusion strategy.

Graham thanked members for their ongoing commitment to participating in the Patient Engagement Forum, and about the important voices and perspectives members bring. The floor was then opened for questions or discussion on any matters the members wanted to raise.

Questions focused on a range of issues, including the impact of COVID-19 on blood and blood product collection, and if the impacts were a point in time occurrence, or if these challenges will be the new reality.

Some asked about the ways formularies in Canada are managed, and how decisions are made about which formularies products will be part of. There was also discussion about where novel molecules and gene therapies for rare diseases could factor into health systems and formulary management in Canada.

There was great interest in the plasma collection strategy, and the relationship with Grifols and timelines for them to open centres. There were also questions about the opportunity to collect additional proteins from plasma collected in Canada, and about the level of demand being seen worldwide.

Eloise Tan, Director, Diversity, Equity and Inclusion, and Priyank Tyagi, Senior Project Manager, then joined the group to lead an overview of the organization's draft Diversity, Equity and Inclusion strategy.

Members saw an overview of the strategy, the key components and areas of focus, and some general timelines.

Participants were then divided into small breakout groups to discuss two questions:

- What would it look like for your communities if this strategy was successfully implemented?
 - What might it change for your communities?
- How do you want to be informed

After the small group discussions, members returned to the main meeting to share a few highlights from their discussions in plenary. Those included:

- A strong desire to stay connected to this topic and this work. Participants shared that many of them are on a similar journey, and would appreciate the opportunity to learn from each other's successes, and perhaps more importantly, from the challenges faced



- The importance of building relationships and earning trust. Recognizing language barriers, and meeting communities where they are, rather than expecting them to seek Canadian Blood Services out
- Tailored community outreach, and being prepared to listen more, and talk less at this stage
- Diversifying the donor base is a noble goal, but the details will be key. Should root this in the fact that this can change and improve lives in the community, it's a tangible thing, not just a "right thing to do"

Next Steps

Canadian Blood Services' annual stakeholder trust survey launched at the conclusion of the joint session and has been sent to all members. We will report back on results.

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

Thank you all for your participation!

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 |
|---|------------------|
| Development of a communications vehicle to help socialize the RFP process and work the goes into being part of it | Under discussion |
| Connect Daphne and Jennifer D re: PDSA registry | Complete |
| Connect Carin with Sarah and Whitney | Complete |
| Kawasaki Disease Symposium Involvement – discuss specifics with Carin | |
| Connect with LLS to discuss podcasts | |
| Schedule DEI follow-up for future meeting | |