

# Canadian Blood Services' Patient Engagement Forum

## Fall 2024 meetings summary report

The Patient Engagement Forum is an opportunity for Canadian Blood Services to engage with patient organizations. The process begins with touch point meetings with members to identify topics that are top of mind for patient organizations. This input supports co-design of meeting agendas and provides an opportunity to gain experience about what each organization is hearing from their members, and if there are any emerging concerns they want to share or are seeking support on. This is also an opportunity to discuss how Canadian Blood Services can work more closely with patient organizations to better meet patient needs. The Forum meets twice annually in the spring and fall, with a collective joint session and individual community sessions for Blood, Plasma, and Stem Cells patient groups.

Stakeholder engagement lies at the heart of these forums, underscoring the critical role of collaboration in shaping Canada's Lifeline. By integrating diverse perspectives, these sessions allow CBS to align its programs with the needs of patients, enhance the safety and efficiency of its services, and prioritize equity and inclusion in healthcare delivery.

The forum's discussions and action plans reflect a shared commitment to:

- Advancing innovation in blood, plasma, and stem cell programs.
- Addressing systemic barriers to donation and donor inclusivity.
- Building trust with underrepresented communities, including Indigenous Peoples.
- Amplifying the voices of patients to inform policy and practice.

Each meeting highlighted the unique challenges and opportunities within its stakeholder community, reinforcing the value of collaborative efforts in improving health outcomes and strengthening CBS's ability to serve all Canadians. This report provides an overview of the discussions, insights, and next steps from these four sessions, highlighting the collective power of stakeholder engagement in achieving transformative change.

## Introduction

The agendas and topics for discussion were determined through outreach to participant organizations. In fall 2024, Canadian Blood Services held individual meetings with 13 patient organizations.

Forum meetings took place on:

- Stem Cells community: Nov. 12
- Blood community: Nov. 21

- Plasma community: Dec. 3
- Joint – all member session: Dec 10

What follows are meeting summaries, highlighting discussion items, key considerations and takeaways and actionable next steps.

## **Participant organizations**

The following organizations and community leaders participated in the Fall 2024 Canadian Blood Services' Patient Engagement Forum, contributing their expertise and insights:

### **Blood Community**

- Canadian Hemophilia Society (CHS)
- Network of Rare Blood Disorder Organizations (NRBDO)
- Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC)
- Leukemia Lymphoma Society of Canada (LLSC)
- Thalassemia Foundation of Canada (TFC)
- Sickle Cell Awareness Group of Ontario (SCAGO)
- Canadian Hemochromatosis Society (CHS)
- Platelet Disorder Support Association (PDSA)
- Atypical Hemolytic Uremic Syndrome (aHUS)

### **Plasma Community**

- AlphaNET Canada (AC)
- Canadian Hemophilia Society (CHS)
- Network of Rare Blood Disorder Organizations (NRBDO)
- GBS/CIDP Foundation of Canada (GBS)
- HAE Canada (HAE)
- Answering TTP Foundation (ATTP)
- Canadian Association for Porphyria (CAP)
- Kawasaki Disease Canada (KD)

### **Stem Cells Community**

- Leukemia Lymphoma Society of Canada (LLSC)

- Sickle Cell Awareness Group of Ontario (SCAGO)
- Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC)
- Myeloma Canada
- Bone Marrow Failure Group at SickKids Hospital

### **Joint Session on Truth and Reconciliation**

- First Peoples Group (Guest Presenter: Heather Watts)
- Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC)
- Answering TTP
- ImmUnity Canada (IC)
- GBS/CIDP Foundation of Canada (GBS)
- Kawasaki Disease of Canada (KD)

These organizations and representatives worked collaboratively with CBS staff, community leaders, and experts to discuss key issues and develop actionable strategies for addressing areas of concern and growing and diversifying Canada's Lifeline. Their contributions were integral to the forum's success.

## **Meeting Summaries**

### **Stem Cells community: Nov. 12, 2024**

The Fall 2024 Stem Cells Community meeting brought together Canadian Blood Services (CBS) staff, patient organization leaders, and stakeholders to discuss collaboration opportunities for raising awareness of stem cell transplantation, growing, and diversifying the stem cell donor registry, and advancing research and support for patients.

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### **Key Discussions and Takeaways**

#### **1. Raising Awareness of the Stem Cell Program**

- **Collaboration Opportunities:**
  - Joint efforts in communication, content sharing, and events to promote stem cell transplantation and donor recruitment.
  - CBS plans to engage patient leaders in education campaigns and provide communications content to amplify patient and donor stories.

- **Event Participation:**
    - CBS to support upcoming conferences and community events in 2025 by providing information and educational materials, recruitment booths, and participation in discussions.
    - Examples include partnering with the Leukemia Lymphoma Society and others to share impactful patient stories.
  - **Next Steps:**
    - Set up one-on-one planning meetings with patient organizations in 2025 to align goals and joint initiatives.
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## 2. Community Engagement and Donor Recruitment

- **Campaigns and Resources:**
    - CBS supports patients and families in hosting community events to recruit stem cell donors, targeting individuals aged 17–35.
    - The “Campaign in a Box” tool has been improved based on feedback to better support patient organizations in their awareness campaigns.
  - **Event Highlights:**
    - Example: A recent community event in Chatham, ON, registered 60 new donors for a patient with lymphoma.
    - CBS prioritizes university events and outreach to diverse communities for donor recruitment.
  - **Next Steps:**
    - Expand the use of the “Campaign in a Box” and provide support for local recruitment events in collaboration with patient organizations.
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## 3. Stem Cell Program Updates

- **Campaign in a Box:**
  - Enhanced usability and design improvements are underway to better serve patient organizations.
- **CAR T-Cell Therapy Infrastructure:**

- CBS's CAR T-cell pilot project lab is nearing completion, with training to begin in early 2025. This marks considerable progress in advancing stem cell-based treatments.
  - **Registry Growth and Diversity:**
    - The stem cell registry is expected to reach 460,000 registrants, with efforts focused on increasing representation from underrepresented communities (e.g., Indigenous, Black, and Filipino populations).
    - Behavioral scientists are providing recommendations to improve engagement with these communities.
  - **Next Steps:**
    - Continue growing the registry, improve demographic data tracking, and implement behavioral insights to enhance outreach efforts.
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#### **4. Collaboration with Cell Therapy and Transplant Canada (CTTC)**

- **Data and Outcomes:**
    - Partnership with CTTC enables CBS to analyze patient outcomes and improve the stem cell donor registry by linking donor characteristics to patient prognosis.
    - Focus areas include data on CAR T-cell therapy and stem cell transplant outcomes for both malignant and non-malignant diseases.
  - **Next Steps:**
    - Continue analyzing data, publish findings, and engage patient organizations in outcome-focused discussions.
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#### **Member Roundtable Highlights**

- **Myeloma Canada (Project Phase Zero):** Addressing barriers to clinical trial enrollment through early screening and navigators to improve trial participation.
- **Leukemia Lymphoma Society of Canada:** Tackling travel barriers to treatment and launching a pediatric study to support families of children with severe illnesses.
- **Sickle Cell Awareness Group of Ontario:** Advocating for access to stem cell transplants and promoting new gene editing therapies like CRISPR for sickle cell disease.

- **Aplastic Anemia and Myelodysplasia Association of Canada:** Raising awareness among healthcare professionals to connect newly diagnosed patients with advocacy resources.
  - **General Collaboration:** All participants emphasized the importance of aligning efforts with CBS to support stem cell recruitment, advocacy, and education.
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## Actionable Next Steps

### 1. Awareness Campaigns:

- Collaborate with patient organizations on content creation, event participation, and leveraging communication tools like the updated “Campaign in a Box.”

### 2. Donor Recruitment:

- Focus outreach on younger, diverse communities through university events, family and community drives, and partnerships.

### 3. Registry Growth:

- Prioritize increasing registration from underrepresented demographics and improving data accuracy.

### 4. CAR T-Cell Therapy:

- Finalize lab infrastructure, begin training, and expand treatment options in 2025.

### 5. CTTC Collaboration:

- Continue research on donor characteristics and patient outcomes, with a focus on improving transplantation processes and publishing findings.

The meeting underscored the importance of collaboration between CBS and patient organizations to advance stem cell transplantation, diversify the donor registry, and support innovative therapies for patients in need

## Blood community: Nov. 21, 2024

The Fall 2024 Blood Community meeting, hosted by Canadian Blood Services (CBS), brought together CBS staff, patient organizations, and stakeholders to address issues related to blood safety, donor policies, and patient care.

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## Key Discussions and Takeaways

### 1. Transfusion Transmitted Malaria and Blood Safety

- **Updates:** Dr. Chantale Pambrun highlighted the potential of nucleic acid testing (NAT) for malaria screening, providing promising progress for those previously deferred donors, particularly those with rare blood types.
- **Challenges:** The test is pending Health Canada approval, though already licensed in the U.S.
- **Impact:** NAT could expand the donor pool, addressing shortages in populations with genetic similarities to patients needing rare blood types (e.g., sickle cell disease).

## **2. Canada's Hemovigilance System and the Blood Safety Contribution Program (BSCP)**

- **Background:** BSCP was created post-tainted blood scandal to ensure national blood safety through surveillance and data aggregation.
- **Concerns:** The program is set to be discontinued in April 2026, shifting monitoring responsibilities to provinces and risking gaps in national data and rare event tracking.
- **Implications:** This could hinder Canada's ability to detect and address adverse transfusion outcomes, especially as other developed nations maintain robust national systems.

## **3. Infectious Disease Surveillance in Blood Donors**

- **Findings:** Surveillance indicates low risks for transfusion-transmitted infections. While HIV and Hepatitis C remain stable or declining, syphilis and Hepatitis B show slight increases due to demographic shifts in donors.
- **Safety Measures:** Stringent testing protocols ensure minimal residual risk for transfusion-transmitted infections.
- **Policy Impacts:** Surveillance informs updates, such as the shift from MSM donor deferrals to risk-based criteria.

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## **Stakeholder and Patient Group Updates**

### **Highlights from Patient Organizations:**

- **Advocacy for New Therapies and Hemovigilance:** Groups like the Canadian Hemophilia Society and NRBDO are focused on ensuring access to innovative treatments and advocating for the continuation of national surveillance systems.
- **Access to Care:** Efforts include addressing barriers for rural patients, airport screening and travel challenges with injectable medications, and equitable access to blood products.

- **Education and Outreach:** Many groups are hosting events, promoting awareness, while tackling funding and staffing challenges to support patients.
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## Action Items

1. **NAT for Malaria:** CBS will continue collaborating with test developers and monitoring the timeline for Health Canada approval. CBS will also keep stakeholders informed in the project's progress and continue to engage with them as the project advances.
2. **Hemovigilance Advocacy:** CBS and patient organizations will coordinate efforts to advocate for a national surveillance system or alternatives.
3. **Surveillance Transparency:** CBS will maintain transparency about infectious disease trends and safety with patient groups.
4. **Event Support:** CBS committed to socializing and supporting patient group conferences and initiatives.

The meeting underscored the importance of collaboration among CBS, patient organizations, and stakeholders to ensure a safe and equitable blood system in Canada.

## Plasma community: Dec. 3, 2024

The Fall 2024 meeting brought together Canadian Blood Services (CBS) staff, patient organizations, and stakeholders to discuss progress in plasma collection, self-sufficiency for immunoglobulin (IG) production, formulary updates, and treatment access.

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## Key Discussions and Takeaways

### 1. Plasma Collections Strategy

- **Progress:** CBS expanded plasma collection centers from 3 to 9, with partnerships like Grifols significantly boosting plasma sufficiency for IG production (from 12.8% to 25-27%).
  - **New Centers:** A center in Thunder Bay will open in March 2025, with the 11th site planned for British Columbia.
  - **Multi-Product Strategy:** CBS is optimizing plasma and whole blood collection to meet donor preferences and system needs.
  - **Grifols Collaboration:** Grifols opened four new centers in 2024, with plans for further expansion in Ontario in 2025.
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## 2. Paid Plasma and Municipal Concerns

- **Municipal Resolutions:** Symbolic opposition in Hamilton and Toronto does not hinder Grifols' operations. CBS continues to engage municipal leaders to clarify the importance of paid plasma and its role in securing Canada's IG supply chain.
  - **Grifols Progress:** Construction of new centers remains on schedule, with the Hamilton center opening in March 2025.
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## 3. Plasma Protein Product Formulary Program

- **Distribution Modernization:** CBS piloted home delivery for plasma protein and related products in Alberta, reducing blood bank workload and improving patient convenience.
  - **Pilot Success:** Over 179 patients received home-delivered medications, with plans to expand the program and conduct patient satisfaction surveys.
  - **Pharmacist Integration in Hemophilia Care:**
    - A pilot program integrating pharmacists in hemophilia centers showed cost savings (\$2 million/year) and clinical improvements (e.g., reduced bleeding rates).
    - Plans are underway to further explore and expand pharmacist roles in hemophilia care across Canada.
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## 4. Product Selection Process

- **Evidence-Based Approach:** CBS collaborates with the Canada Drug Agency to evaluate new plasma products, incorporating clinical, economic, and patient feedback prior to provincial funding approval decision-making.
  - **Upcoming Reviews:** Products like Altuviiiio and recombinant ADAMTS13 are under review, with decisions dependent on provincial pathways.
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## 5. Patient Organization Roundtable

Key challenges discussed:

- **Access to Treatments:** Delays in accessing new therapies (e.g., Orladeyo for HAE) and long wait times for treatment in emergency settings.
- **Data Gaps:** Lack of detailed data on plasma product usage in hospitals – due to separate hospital and provincial data tracking.

- **Advocacy Efforts:** Ongoing patient advocacy priorities include funding, gene therapy reimbursement, and a national hemovigilance system.
  - **Pilot Programs:** Organizations like NRBDO and CHS emphasized the need to expand pharmacist programs and improve IG usage practices.
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## Action Items and Next Steps

### 1. Plasma Collection:

- Monitor Thunder Bay center opening and progress on the 11th site in BC.
- Expand multi-product collection and refine marketing strategies to attract plasma donors.

### 2. Paid Plasma:

- Continue dialogue with municipal leaders to support Grifols operations.
- Ensure construction and permitting for new centers remain on track.

### 3. Distribution and Formulary:

- Expand Alberta's pilot for home delivery and integrate more products based on patient feedback.
- Promote pharmacist integration in hemophilia centers nationwide.

### 4. Stakeholder Engagement:

- Patient organizations will share advocacy efforts related to hemovigilance funding and equitable access to new therapies. CBS will communicate their efforts and learn of patient engagement efforts through the NRBDO.
- Increase transparency and education about plasma product distribution and safety.

The meeting highlighted CBS's progress in plasma collection, innovative distribution models, and the importance of collaboration with patient groups to ensure equitable access and efficient delivery of plasma-derived therapies.

## Joint session: Dec. 10, 2024

The Fall 2024 Joint Session welcomed Indigenous leader and expert **Heather Watts with First Peoples Group** to facilitate a learning and discussion session focused on **Truth and Reconciliation**, emphasizing collaboration with Indigenous communities to address historical

injustices, improve representation, and take action to rebuild trust in healthcare and donor systems. Canadian Blood Services (CBS) shared its **Reconciliation Action Plan**, which incorporates input from Indigenous leaders, and engaged participants in discussions about reconciliation, education, and practical steps for advancing equity and inclusion.

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## Key Highlights

### 1. Opening Remarks and Purpose

- **Commitment to Reconciliation:** CBS aims to improve relationships with Indigenous communities, focusing on meaningful engagement and addressing barriers in healthcare and donor systems.
  - **Heather Watts:** An Indigenous leader from the Mohawk and Anishinaabe communities, Heather shared her expertise on reconciliation, highlighting historical context and actionable strategies.
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### 2. Understanding Indigenous Diversity

- **Cultural Distinctions:** Participants learned about the unique histories and identities of First Nations, Métis, and Inuit peoples, emphasizing the importance of recognizing their distinct needs and contributions.
  - **Challenges and Displacement:**
    - Many First Nations people live off-reserve (63%), often due to urban migration and displacement.
    - Ottawa hosts the largest Inuit population outside Nunavut, driven by healthcare access issues in the North.
  - **Building Trust:** Heather stressed the need for organizations to approach Indigenous communities with respect, understanding their histories and leadership structures.
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### 3. Historical and Ongoing Healthcare Impacts

- **Legacy of Mistrust:** The session addressed the harmful legacy of Indian hospitals and Inuit sanatoriums, which included unethical medical experiments and inadequate care.
- **Health Inequities:** Indigenous communities continue to face higher rates of mental health challenges, overcrowded housing, and inadequate healthcare in remote areas.
- **Call for Transparency:** Building trust requires addressing past harms and ensuring culturally informed, respectful patient care.

#### 4. Commitment to Reconciliation

- **Key Principles:**
    - Start with **truth**: Acknowledge historical injustices before focusing on reconciliation.
    - Reconciliation requires **individual and organizational responsibility**.
    - Tailor action plans to the specific needs of Indigenous communities served.
  - **Framework for Change:**
    - **Symbolic**: Actions like land acknowledgments and observing reconciliation events.
    - **Substantive**: Providing resources, education, and sharing Indigenous stories.
    - **Systemic**: Structural changes, including culturally safe policies and Indigenous representation in governance.
  - **Education and Resources**: Participants were encouraged to use tools like the University of Alberta's free "Indigenous Canada" course for ongoing learning.
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#### 5. Challenges and Solutions

- **Language Sensitivity**: The term "stakeholder" was identified as problematic in the context of reconciliation. CBS will collaborate with Indigenous leaders to find culturally appropriate alternatives, such as "rights holder."
  - **Proposed Small Steps for Smaller Organizations:**
    - Begin with board-level conversations and symbolic gestures.
    - Use existing resources to guide reconciliation efforts.
    - Focus on culturally safe care and patient-centered engagement.
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#### Group Discussions

##### Discussion #1: Truth

- **Reflection Questions:**
  - What has gone well, and what challenges remain in reconciliation efforts?

- How can organizations educate and engage their communities on reconciliation?

- **Key Takeaways:**

- Start with small, meaningful actions.
- Build trust through long-term relationships and respectful engagement.
- Incorporate reconciliation into education and awareness campaigns.

## **Discussion #2: Language and Representation**

- Participants discussed the importance of using respectful, inclusive language and ensuring Indigenous voices are represented in organizational decision-making.
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## **Next Steps**

### **1. Education and Awareness:**

- Share session resources, including summary slides and recordings, with participants.
- Encourage organizations to integrate education on Indigenous histories and reconciliation into their activities.

### **2. Practical Actions:**

- Begin with symbolic gestures like reconciliation statements or land acknowledgments.
- Work with Indigenous leaders to develop culturally informed policies and practices.

### **3. Collaboration and Feedback:**

- Engage with Indigenous communities for guidance on action plans and language use.
  - Establish partnerships to align goals and support reconciliation efforts.
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## **Conclusion**

The session highlighted the importance of truth, trust, and actionable steps in fostering reconciliation between Indigenous and non-Indigenous communities. Participants expressed a commitment to learning, collaboration, and meaningful engagement to advance equity and inclusion in healthcare and beyond.

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## Closing

The Fall 2024 Canadian Blood Services' Patient Engagement Forum demonstrated the transformative potential of collaboration and dialogue across diverse stakeholder communities. By convening representatives from the Blood, Plasma, and Stem Cells communities, alongside a dedicated session on Truth and Reconciliation, CBS reinforced its commitment to advancing equitable healthcare, innovation, and inclusivity.

These sessions not only highlighted critical challenges in blood safety, plasma sufficiency, and stem cell transplantation but also underscored the importance of fostering trust and meaningful engagement with Indigenous communities. Through open dialogue and actionable insights, CBS and its partners have strengthened their shared resolve to enhance patient care, promote education, and ensure representation in donor systems.

As we move forward, the insights and action items identified during these meetings will serve as a foundation for continued progress. CBS is deeply grateful to the patient organizations, stakeholders, and community leaders who contributed their expertise and perspectives. Together, we are building a more inclusive and resilient healthcare system—one that reflects the needs and aspirations of all Canadians.