

# Consultations with Trans and Gender Non-Binary Communities — 2016 Summary Report

## What we heard: Top key themes from in-person community consultations

- **Behaviour-based donor criteria** are essential for building a screening process that is more respectful of trans and gender non-binary individuals. Without these criteria, the process is based more on gender and identity assumptions, rather than behaviours that pose a risk to the blood system. Certain risk factors are independent of gender and can apply to everyone. As a result, very explicit behaviour-based questions would reduce the need to ask questions that identify people as trans individuals.
- **Better staff training** is needed to screen trans and gender non-binary donors in a more respectful way. A more consistent and standardized approach on teaching proper terminology, as well as sensitivity training, would help Canadian Blood Services' staff better understand and interact respectfully with trans and gender non-binary individuals. It would also help provide more consistency in donor experiences.
- **Clearer screening processes** are needed. It is uncertain how screeners identify individuals as trans and gender non-binary. There were many questions about why certain questions are asked, and why criteria for trans and gender non-binary donors are needed.
- **More consistent screening processes** would help reduce the feeling of discrimination that trans and gender non-binary individuals currently experience, such as being deferred for risk behaviours or indicators that other groups (e.g., cis women) may also have. All donors should be asked the same questions, regardless of sex or gender, and some of the questions need to be revisited.
- **More support for research and data** is critical for understanding risk behaviours within the trans and gender non-binary communities, especially as demographics may have changed over time. More robust Canadian data is also needed. This research is critical for Canadian Blood Services' efficacy moving forward.

## What we can do

- **Follow-up communications:** Keep the trans and gender non-binary communities informed of Canadian Blood Services' actions related to policy or screening changes.
- **Short-term actions:** Implement a training program for front-line staff focused on better understanding and respecting trans and gender non-binary individuals. Engaging the trans community (paid contracts) will be critical for this initiative.
- **Short- to intermediate-term actions:** Explore how to modify clinic processes to allow trans individuals to select the gender with which they identify.

- **Longer-term actions:** Move forward on research related to the donor deferral policy for men who have sex with men (MSM) and explore options for changing to behaviour-based screening criteria. The results of this research could create a more favourable screening process for some trans individuals.

### Purpose and introduction

This report summarizes the key themes from two in-person consultations with trans and gender non-binary communities. These consultations — held in Vancouver on Nov. 17, 2016, and in Toronto on Dec. 8, 2016 — brought together a number of trans and gender non-binary individuals from Vancouver, Edmonton, Toronto and Ottawa.

The goal was to have an in-depth, solution-focused discussion with people in the trans and gender non-binary communities on improving screening processes for donor eligibility. The focus was on engaging:

- Individuals who have attempted to donate at one of Canadian Blood Services' clinics but have had a negative experience.
- Regular donors who have found a comfortable way to navigate the screening process and successfully donate.
- Individuals who are not donors but have contacted Canadian Blood Services to offer guidance on how to be more respectful of all trans and gender non-binary donors.
- Individuals who have always wanted to donate but were concerned about being treated differently or respectfully at a clinic.

### Background and context

Over the last few years, a small but increasing number of potential donors have identified as trans or gender non-binary (about 30 to 50 individuals). In August 2016, Canadian Blood Services introduced national standardized screening criteria to recognize that these individuals would like to donate blood. However, these criteria were heavily criticized by individuals from the trans and gender non-binary communities. As a result, Canadian Blood Services has committed to working with members of the community to improve the donor screening process to ensure all potential donors are treated with respect and dignity. The consultations would also provide Canadian Blood Services with an opportunity to share information on the blood system and how it is managed, how blood and blood products are processed and safety concerns for both donors and recipients.

### Planning and process design

In planning these consultations, Canadian Blood Services convened a planning committee comprising mostly trans and gender non-binary individuals. This committee participated in a series of teleconference calls and email communications to help develop the consultation agenda, including providing input on the focus question and process design. A key task for committee members was to leverage their own networks to identify and invite participants to the consultations.

### **Canadian Blood Services information shared with stakeholders**

To ensure consultation participants were aware of Canadian Blood Services' role as the operator of the blood system for Canada outside of Quebec, a structured presentation was shared to convey information about how the blood system works and the details of the blood donor screening process.

By operating over 14,000 blood donor clinics per year across Canada, collecting nearly a million donations and processing them at nine production sites in seven provinces, Canadian Blood Services meets the needs of patients in over 600 Canadian health-care facilities.

Our 4,300 staff members and 17,000 volunteers interact with almost 400,000 regular blood donors and over 380,000 Canadians who have registered for the stem cell donor program. We know that each interaction is important to the individuals involved.

Canadian Blood Services has the mandate to operate Canada's blood supply in a manner that gains the trust, commitment and confidence of all Canadians. This mandate was given to the organization at its creation as part of the resolution to the tainted blood tragedy. This crisis was the largest public health disaster in Canadian history. Over 2,000 Canadians were infected with HIV, 30,000 were infected with hepatitis C, and \$2.7 billion in government compensation was paid to the victims. This history makes us very careful about making changes to the blood system that would cause Canadians to lose trust in us. So, changes are made cautiously and with evidence in hand.

We have a layered approach to blood safety. The first principle is to have people donate blood who are most likely to be free of infections that could be transmitted to patients. We do this by asking screening questions of donors to determine whether they fall into one of the groups of people who are at higher risk. At this time, our system is not set up to perform individual risk assessments the way a physician might do for an individual patient. Screening questions allow us to have the highest probability of having negative test results from tested blood. We use this strategy because testing does not work perfectly every time and even the most modern blood screening tests are not sensitive enough to detect early infections.

For the screening of trans donors, we seek to have a respectful approach to potential donors, and also to gain the information we need to understand whether a donor may present a safety risk. Our main concerns are the risk of transmission of antibodies in the blood of donors who have ever been pregnant and the risk of infectious disease transmission. A new standardized screening process for trans donors, including questions to address these risks, was brought into our clinics in August 2016. We know this process has not been well received, and we are reaching out to stakeholders to look at how to improve our trans donor assessment process while maintaining the safety of the blood supply.

### **Key themes emerging from the consultation**

#### **Behaviour-based donation criteria**

Participants strongly urged Canadian Blood Services to move toward behaviour-based donation criteria that do not refer to gender or sexual identity. Recognizing that this will take time and will require Health Canada's approval, they believe this change is essential to achieve a more respectful screening process for

trans and gender non-binary individuals. Without this, they feel the process is based more on gender and identity, rather than behaviours that pose a risk to the blood system.

Participants generally felt that gender identity and behaviour need to be separated since certain risk factors are independent of gender and can apply to everyone. Behaviour-based donor criteria would reduce the need to ask questions to identify people as trans. Several participants emphasized the need for very explicit screening questions that ask about specific behaviours, such as having anal sex or having been pregnant, and not about sex (current or assigned at birth), gender or anatomy. They felt this approach to screening would better ensure that Canadian Blood Services gathers the information it needs.

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### “Gender is largely irrelevant.”

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Participants challenged assumptions embedded in the screening process that they felt reveal a perceived lack of understanding about the nuances of gender and identity. They felt that the screening process overlooks both the diversity and complexity of individual experiences and circumstances, particularly around sexual activity. For example, many participants stated that the current criteria unfairly screen out gay men. Some participants also claimed that the process is discriminatory toward trans individuals who are sexually active (even if they are in a committed relationship).

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### “Don’t assume that people with various lower body parts have certain types of sex.”

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Participants felt that the current screening process is unsatisfactory, as screeners have varying attitudes and abilities in terms of interacting respectfully with trans and gender non-binary individuals who wish to donate. Overall, participants emphasized that moving to gender-neutral, behaviour-based screening would also be more evidence-based, objective and defensible.

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### “[Criteria should] not be based on an arbitrary definition of who I am and what activities I engage in.”

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#### **Better staff training**

Another major recommendation coming from participants is the need for consistent training to better equip Canadian Blood Services’ staff to screen trans and gender non-binary donors more respectfully. More specifically, a standardized approach (including sensitivity training) implemented across the country would facilitate the use of proper terminology, and help staff to better understand the community. This

training should guide staff on how to ask questions and interact respectfully with trans and gender non-binary individuals. The training would also help provide more consistency in donor experiences, rather than “leaving it up to the screener.”

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**“When I donated in the past, the process was completely different based on who I was talking to.”**

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Participants had many questions about how Canadian Blood Services currently trains staff, particularly front-line staff. Some participants appreciated that Canadian Blood Services has worked with Egale to provide trans and gender non-binary training workshops and modules, but noted that much more is needed to standardize the approach across the organization. Without this, the transfer of competencies will take longer and will rely on the efforts and attitudes of trained employees to pass on what they have learned to their colleagues.

Participants expressed interest in hearing about concrete next steps for implementing training, with many offering ideas to help. Some felt that trans and gender non-binary people (including both trans feminine and trans masculine) must lead or at least be involved in training, with their efforts properly remunerated. In addition to helping train staff, a few participants suggested having trans and gender non-binary people visit a clinic and share their experience with staff who could ask them questions outside of the screening context.

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**“[Training] has to be done by people with the experience so it can be conveyed and not have cis people do it for us.”**

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### **Clearer screening process**

Many participants were concerned with what they saw as an overall lack of clarity around Canadian Blood Services’ screening process, particularly in terms of how individuals are identified as trans and gender non-binary by screeners. Canadian Blood Services explained that individuals can be identified in various ways. In general, many participants sought clarification and elaboration to better understand why certain questions are asked (e.g., MSM, gender, pregnancy), and why criteria for trans and gender non-binary donors are needed. They also probed on how Canadian Blood Services defines risk related to certain activities, such as drug use, jail time and sex work, and how the process differs once someone is identified as either male or female.

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**“How do you flag someone as trans?”**

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As participants learned more about Canadian Blood Services' perspective on blood safety risks (i.e., transfusion-related acute lung infection (TRALI) for blood recipients, bloodborne infections, HIV, hepatitis, etc.), many felt the screening process was still difficult to understand or did not reflect some of the rationale provided. Others felt the process relies too heavily on the screener's discretion. Again, as noted in the first theme, most participants expressed strong support for a behaviour-based screening process that removes the need for gender identification. They think the current screening process is overly complicated.

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**“You’ve confused [needing to treat trans people with dignity] with protecting the blood supply — these don’t exclude each other.”**

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### **More consistent screening process**

Another major theme emerging from the consultations is the need to develop a more consistent screening process. While similar to previous themes, this captures more specific concerns around how trans and gender non-binary individuals feel discriminated against through the current process.

Some participants perceive that Canadian Blood Services favours cis women. In their view, these donors may have the same risk behaviours or indicators that effectively screen out trans and gender non-binary individuals, as well as gay men (e.g., sex with MSM, bloodborne infections). They believe that a time-based abstinence deferral (12 months) unfairly disqualifies some individuals.

While Canadian Blood Services explained it constructs and asks certain questions to develop “big risk categories,” participants advised that all donors should be asked the same screening questions, regardless of sex or gender; this would help prevent discrimination. They also recommended that the organization provide a stronger rationale for asking certain questions. Some participants recommended revisiting the donor questionnaire. For example, some felt that the question on pregnancy should be reframed so that the prospective donor is clearer about what is being asked and why.

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**“Just treat everyone the same.”**

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### **More support for trans research and data**

Several participants pointed out limitations with the research underlying the rationale for the current screening process, particularly in terms of how risk behaviours are associated with certain individuals or groups. Some participants identified the need for better and more recent research on risk behaviours and indicators, given the change in demographics over time (e.g., MSM and HIV rates). This research would include studies that specifically focus on the trans and gender non-binary communities. Many felt this research is critical for Canadian Blood Services' efficacy moving forward. Both Canadian Blood Services and participants agreed on the need for robust Canadian data, with some participants suggesting that

Canadian Blood Services request support and resources from Health Canada to conduct the necessary research (including engaging transgender researchers) on a national level.

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**“We have a lot of research about risky behaviours, but we don’t have research that says this identified group identifies with that behaviour.”**

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Some participants also noted broader issues with the current state of research, such as the lack of follow-up action and the fundamental issues around historical and systemic inequality. Additionally, a few participants asked about using the blood donated from “high-risk” individuals — who may be otherwise deferred — for research purposes. Canadian Blood Services explained that its netCAD Blood4Research facility at the University of British Columbia does just that — it provides this option for individuals who are not eligible to donate at a regular clinic.

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**“Most of the research sits on a shelf.”**

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**“A lot of research is based on underlying homophobia and transphobia, which is the starting point for research.”**

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#### **Revisit lower gender-affirming surgery criteria**

While related to other themes, this specific theme is about participants’ strong concern with Canadian Blood Services asking questions about lower gender-affirming surgery (GAS). Participants explained that this is a highly sensitive topic for most trans and gender non-binary people. Many felt it should not be included in the screening process, as it is deeply offensive. They also explained that this question is based on false assumptions that could lead to unnecessary deferral and discrimination, as there is considerable diversity among individuals in the community. There are different types of lower GAS; for example, some don’t give individuals the option to have penetrative sex.

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**“There are many holes in that policy [of asking about lower GAS surgery].”**

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“Some individuals want surgery but some don’t – they need to be looked upon equally.”

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“It doesn’t make a difference what surgery they have had — it’s really about their blood.”

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Many participants suggested removing questions about lower GAS from the questionnaire, arguing that there are more meaningful, inclusive and specific questions (e.g., pregnancy, types of sexual behaviour) that could be asked to provide Canadian Blood Services with the information it needs. It was noted that there are several jurisdictions in Canada that do not require lower GAS to change sex or gender markers on a person’s identification. Again, these concerns reflect the most prominent theme voiced by participants — the need for gender-neutral, behaviour-based criteria.

### **Recognize gender non-binary individuals**

Several participants noted that the current screening process does not recognize or accommodate gender non-binary individuals. They urged Canadian Blood Services to address this issue with thoughtful, respectful question design. It was also pointed out that changing demographics in the community will require this. Without this type of adjustment, gender non-binary people will continue to be at risk of not being treated respectfully during the screening processes.

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“Don’t push [individuals] into categories.”

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“The fastest-growing group of trans people are gender non-binary and gender-fluid people.”

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### Other points

- **Trans women and MSM are different and should be treated differently:** While some recognized the progress that Canadian Blood Services has made on the MSM criteria journey, many participants did not like how trans women (particularly those with a male partner) and MSM are often “lumped into” the same high-risk category.

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“I am trans female and my identity is female — to put me in a box as male is offensive, as is implying that I am gay.”

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- **Consider how the process marginalizes vulnerable groups:** A number of participants stressed that the identified high-risk groups are also often the most vulnerable and stigmatized populations — not only trans and gender non-binary people, but also sex workers, drug users and ex-prisoners. Because of this, some felt that the blood screening process was very problematic because it helps perpetuate stigma and marginalization. Again, they argued that this is another reason for more specific risk behaviour-based criteria.

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“Many of us have been in precarious situations.”

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“It is oppressive and protects the majority.”

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- **Respect and ensure individual privacy:** Some participants had questions about how privacy is protected during donor screening. They expressed concerns about being asked intrusive questions, and were worried about being screened in a room that is not private.

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“We need our privacy and not to be outed in a public space — that is a huge issue and if you mess up you may kill someone.”

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### Next steps

Most participants were very interested in follow-up and continued communication with Canadian Blood Services, particularly on potential improvements to the screening process. Some remarked that now is the time to seek change, given changing public perceptions and a federal government that is more open to

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demonstrating inclusiveness. A few participants also stated that they plan on visiting a blood donation clinic, documenting their experience and sharing it with the group and Canadian Blood Services.

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**One participant's post-consultation donation experience: "In all, I feel like this donation has been the best experience that I've had since donating. I feel CBS is moving into the right direction, even though there are many more improvements to make."**

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Follow-up items include:

- Report on the community consultation to be provided early in 2017.
- Provide participants with information (including timelines) on incremental changes that can be made by Canadian Blood Services.
- Explore timelines for question changes (e.g., removing questions about lower GAS), recognizing that this would require Health Canada approval.
- Explore how to modify clinic processes to allow trans individuals to select the gender with which they most identify.
- Explore timelines for broader policy change (i.e., behaviour-based criteria).
- Create opportunities for trans and gender non-binary individuals to be part of the training process for front-line staff.

Timely updates on any changes to the above follow-up items will be shared on Canadian Blood Services' website: [www.blood.ca](http://www.blood.ca).