Canadian Academy of Health Sciences
Académie canadienne des sciences de la santé

Fetal Alcohol Spectrum Disorder in Canada:

Engagement Report

June 2025

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Introduction

This report provides additional information about the engagement process undertaken as part of the Canadian Academy of Health Sciences' (CAHS) assessment on Fetal Alcohol Spectrum Disorder (FASD). This assessment was undertaken to help identify challenges and opportunities to strengthen Canada's approach to addressing FASD.

For the assessment, the Public Health Agency of Canada[1] charged CAHS with answering four key questions:

1. What is needed to support broader uptake of the **Canadian FASD Diagnostic Guidelines in Canada**?
2. What are the clinical/community and federal/provincial/territorial challenges associated with **case identification and data collection** in Canada?
3. How can FASD **prevention** activities be strengthened to support the overall objective of reducing the prevalence of FASD in Canada?
4. What tools, resources and supports are needed to improve outcomes for those with FASD across the life course?

The completed assessment identified key findings with potential pathways forward for policy makers. These key findings were informed by research evidence, policy scans, expert review, and the comprehensive engagement process described in this report.

Collecting information through multiple engagement mechanisms is a way to identify gaps in knowledge and practical challenges that may not be captured by research or policy evidence. As such, a key part of this assessment was engaging with people with FASD, their families and caregivers, and professionals with expertise in the area. CAHS was committed to hearing from these participants to make sure our key findings would be both relevant and practical. The insights gathered through this engagement process provided detailed information about the experiences of people with FASD and their families, as well as the systemic challenges faced by professionals and organizations. We greatly appreciate participants' contributions to this engagement process.

In this report, we outline the process and methods we used, including their strengths and limitations; who participated; and how we used the information we gathered.

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[1] This assessment process was supported by funding from the Public Health Agency of Canada. The views expressed herein do not necessarily represent the views of the Public Health Agency of Canada.

Our process

The engagement process was conducted in two separate rounds, each with a specific purpose and each including multiple ways to participate. The first round collected information on barriers, challenges, and opportunities related to the four questions from the Public Health Agency of Canada. This round also generated suggestions on strengthening Canada's approach to FASD. In the second round of engagement, we presented preliminary findings and explored these with participants to validate, amend, and refine them.

To support broad and inclusive participation, we offered a variety of ways to engage: live virtual sessions, small group conversations for people with FASD, written surveys, asynchronous online discussions, Indigenous-led sessions, and several interviews with provincial and territorial government representatives. Each engagement mechanism was offered in English and French.

Across all engagements, we reached a total of 1622 participants. (Note that some individuals may have participated more than once across different engagement mechanisms, so this number does not necessarily represent the number of unique individuals.)

Out of the 1622 total participants, 377 (23%) had living experience of FASD (defined here as people with FASD and people close to them, including family and caregivers). Figure 1 shows a breakdown of how many participants were reached through the different engagement mechanisms. Indigenous[2] and Indigenous-serving[3] persons and organizations were invited to all engagement mechanisms, and Indigenous participation was not limited to the Indigenous-led sessions held exclusively for Indigenous participants.

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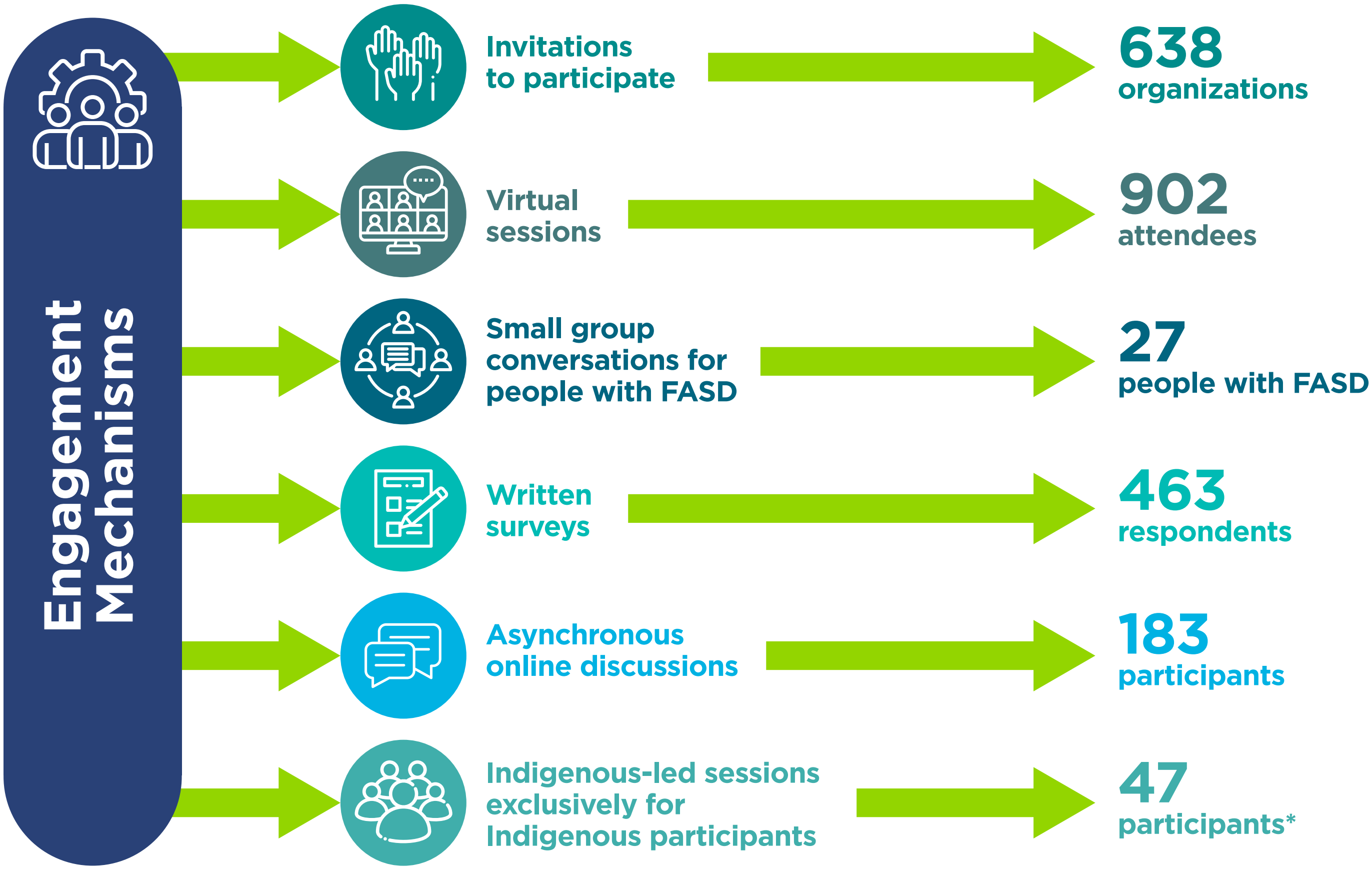
[2] "Indigenous" is defined here as an organization or individual self-identifying in response to survey/poll questions and/or a thorough web search into the organization's leadership, history, and mission.

[3] "Indigenous-serving" is defined here as an organization or individual that serves a large Indigenous population, has Indigenous perspectives integrated into the organization's mission and vision, and/or is strongly involved in services specifically designed for Indigenous individuals.

Figure 1: Outreach and engagement across both rounds



* At least 165 Indigenous and Indigenous-serving persons and organizations were also involved in the other engagement mechanisms.

Virtual sessions

We conducted twelve live virtual sessions open to the public, six sessions in each of the two rounds. These two-hour live virtual sessions took place on Zoom, were moderated by the Assessment Chair, and offered English and French translation. Employing a multimodal approach, the moderator posed questions orally, in writing, and through Zoom polls. Participants responded to the moderator's open-ended questions in writing using Zoom's webinar question-and-answer (Q&A) feature. The Q&A feature also allowed attendees to upvote any comments or answers they wished to endorse. Throughout the session, the chair summarized her understanding of the written comments and asked participants follow-up questions. After the webinar ended, a Q&A report was automatically generated for subsequent analysis.

In total, across both rounds, these twelve sessions attracted 902 attendees from all provinces and territories in Canada. (Some attendees may have participated in more than one session, so this number does not necessarily reflect the number of unique individuals engaged through this process.)

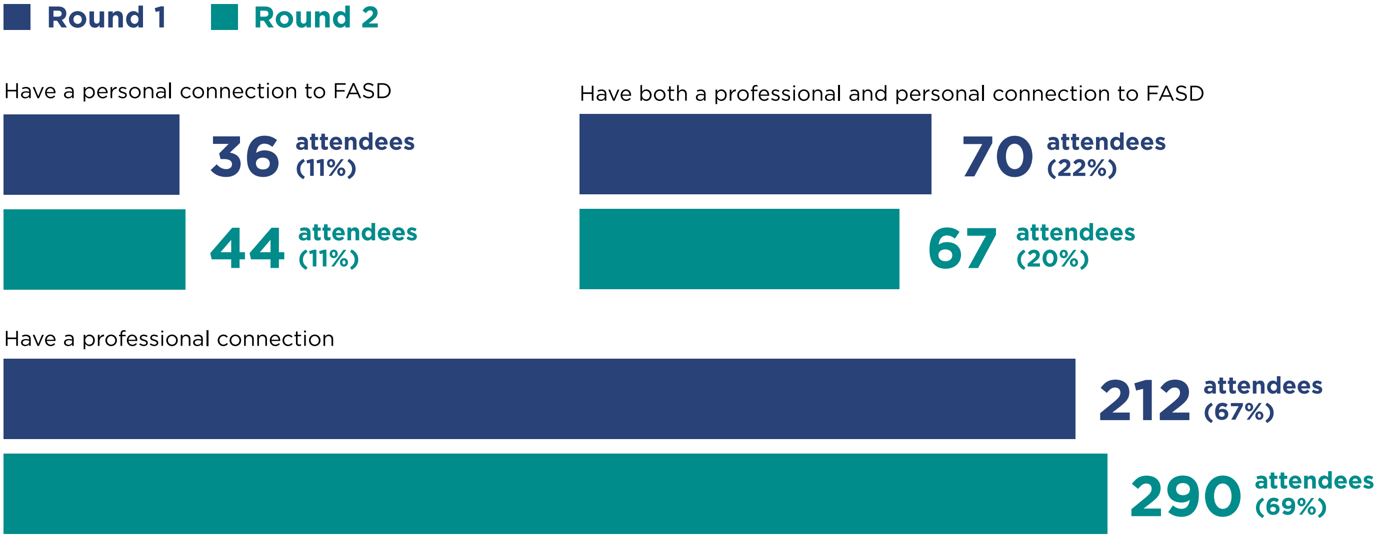
Participation by geographical region, where participants provided this information, is shown in Table 1.

Table 1: Virtual session participants by geographic region

Geographic Region	Round 1	Round 2
British Columbia	86 (18%)	37 (15%)
Manitoba/ Saskatchewan/ Alberta (Prairies)	113 (23%)	71 (28%)
New Brunswick/ Nova Scotia/ PEI/ Newfoundland and Labrador (Atlantic)	50 (10%)	10 (4%)
Ontario	181 (37%)	113 (44%)
Quebec	22 (5%)	7 (3%)
Northwest Territories/ Yukon/ Nunavut (North)	32 (7%)	17 (7%)

Across all twelve sessions, as shown in Figure 2, attendees reported having either a personal connection (meaning they have FASD or are close to someone who does), a professional connection (meaning they work in an area related to FASD), or both a personal and professional connection.

Figure 2: Virtual session participants' connections to FASD



Round 1

In the first round (January 2024), sessions were organized regionally, with one session each for British Columbia, the prairies (Alberta, Saskatchewan, and Manitoba), Ontario, Quebec, the Atlantic provinces (New Brunswick, Newfoundland and Labrador, Nova Scotia, and Prince Edward Island), and the North (Yukon, Northwest Territories, and Nunavut). Through this, we aimed to capture the challenges and opportunities faced in different parts of the country, recognizing the diverse geographic, socioeconomic, and cultural contexts that shape FASD-related experiences. These six sessions focused on gathering input regarding barriers to progress, potential improvements, and strategies for FASD prevention and support. Questions to participants centred on:

- How prevention activities can be strengthened or improved to help reduce prevalence of FASD in participants' regions and across the country
  - Key concerns and challenges related to prevention
  - Prevention initiatives that could be implemented or scaled up, and how to do so
  - Other ways prevention activities could be strengthened or improved to help reduce prevalence of FASD in participants' regions and across the country
- The tools, resources and supports needed to improve outcomes for people with FASD
  - Which support areas are currently furthest ahead
  - Which areas have the most room for improvement
  - How to build on or expand successes
  - Tools, resources, or supports that are currently making the greatest difference for people with FASD
  - Tools, resources and supports that are currently most needed to improve outcomes for people with FASD

The sessions also addressed related topics such as diagnosis, resourcing, policy, and stigma reduction. Participant comments on all FASD-related topics were included in our analysis of the data, even if these comments did not relate directly to the questions asked, in order to capture participants' full input and to identify what they viewed as important.

Across all six sessions in round one, attendees generated over 2,000 written comments. To analyze this information, all comments were first stripped of personally identifying information and anonymized. For each region, the comments were initially analyzed using an artificial intelligence tool to provide a starting set of top themes and sub-themes for each. A single reviewer then tested this initial thematic structure by reviewing all comments against the initial thematic structure. This process resulted in a modified set of themes/sub-themes, which the reviewer used to thematically code all of the comments. The comments were organized into twenty main themes, each with one to twelve sub-themes. As noted in a later section

(How we used this information), these results were verified by conducting a second independent review of the comments that evaluated the thematic structure and coding, and produced a final integrated report that captured results across all engagement mechanisms to inform the writing of the report.

Round one attracted 484 attendees in total. Participants ranged in age from 18 to over 74 years old.

Round 2

In round two (April-May 2024), the live virtual sessions were organized not by geography but around six themes we saw emerging from the research evidence, policy scans, and first round of engagement. In addition, feedback during round one made it clear that virtual sessions dedicated to people with FASD would be helpful and we included these in round two. While there were important variations regionally, there were also many shared challenges and opportunities. Organizing by theme allowed participants to choose to attend sessions focused on the subject matters of greatest relevance to them and let us dive deeper into each topic while still remaining alert to regional differences.

The six themes and the preliminary findings for each were as follows:

1. Essential Needs: finances, employment, housing
    - Resources and supports for employers
    - Employment supports for people with FASD
    - Life skills training for people with FASD
    - Stable and sufficient financial supports for people with FASD
    - Appropriate housing supports for people with FASD
2. Supports and Inclusion: education, aging and transitions, inclusion (acceptance, public education, community participation), collaboration and engagement
    - Stigma-free and blame-free language in FASD messaging, public education, interventions and professional training
    - Collaboration among schools, communities, and caregivers
    - Resources for educators, combined with training, guidance and supports to use them
    - General screening of functional abilities for all students
    - FASD-inclusive transition supports
3. Health Services and Diagnosis: healthcare, diagnosis and assessment
    - Desired Outcome: Better data on FASD prevalence
    - Early intervention, based on functioning, without waiting for a diagnosis
    - Improved access to assessment and diagnostic consistency (Canadian FASD Diagnostic Guidelines)
    - Supports from a range of health professionals for people with FASD

4. Legal Structures: child welfare system, criminal justice system
    - Access to supports that can help families stay together
    - Supports for successful independence of youth in care
    - Specialized courts relevant to FASD
    - Alternative sentencing for people with FASD
5. Prevention: reducing FASD prevalence
    - Stigma-free and blame-free language in FASD messaging, public education, interventions and professional training
    - School-based programs with universal education on high-risk behaviours
    - Systematic screening for alcohol use
    - Access to contraception
    - Alcohol policy interventions similar to tobacco
    - Effective supports to address the individual, social, cultural and environmental risk factors for risky alcohol use
6. Living Experience: only open to people with FASD
    - People with FASD and their families are accepted
    - People with FASD have the supports they need in learning environments
    - Job supports for people with FASD
    - Life skills training
    - Supports for successful independence of youth in care
    - Access to assessments and supports for adults with FASD

For all sessions, moderators presented the key findings, including desired outcomes and possible pathways forward, and asked the following questions:

- What do you think of this finding?
- What would be needed to address this finding in Canada?

For the first five of these sessions, as in round one, participants used Zoom's question-and-answer (Q&A) feature to answer questions. Two reviewers attended all sessions, then reviewed and analyzed the data.

The sixth session had a different format. For this session, open only to people with FASD, participants engaged in a live discussion with the moderators. This gave participants the option to speak or to contribute in writing, depending upon their preferences. Feedback was collected by two scribes, who also reviewed and analyzed the data from this session.

For all six sessions, the reviewers looked at participants' feedback and tagged and grouped concepts and content deemed similar. Responses were grouped according to the key themes, desired outcomes, and possible pathways forward. This allowed the reviewers to identify key topics or sub-themes, along with one to four representative participant quotations per topic. Results were then compared and reconciled between reviewers.

In round two, a total of 418 attendees examined the preliminary key findings related to each of these themes. By thematic session, participation was as follows:

1. Essential Needs: 114 attendees (27% of total attendees in round two)
2. Supports and Inclusion: 91 (22%)
3. Health Services & Diagnosis: 79 (19%)
4. Legal Supports for People with FASD: 60 (14%)
5. Prevention: 63 (15%)
6. Living Experience: 11 (3%)

The diversity of participants who joined meant that these sessions also captured regional variation within themes. Geographically, the virtual sessions had attendees from all provinces and territories in Canada. Four hundred and two (96%) attendees participated in English, with 15 (4%) attendees participating in French, and one participant participating in both languages.

In round two, further information on organizational affiliation was available. This demonstrated that a broad spread of organizations were represented in these sessions:

- FASD supports or services, including assessment/diagnosis: 103 organizations (34.6% of all organizations participating)
- Government (provincial/territorial): 62 (20.8%)
- Government (federal): 19 (6.4%)
- Professional association: 19 (6.4%)
- Educational institution or training facility: 12 (4.0%)
- Indigenous nation: 11 (3.7%)
- Research centre or network: 8 (2.7%)
- Other non-government organization: 26 (8.7%)
- Other: 38 (12.8%)

Small group conversations with people with FASD

During round one of the virtual sessions, we received feedback from people with FASD that live sessions with the option to speak could be more accessible to some than formats requiring participants write comments (as in the virtual sessions and the first round of asynchronous online discussions). In response, CAHS hosted two small group conversations for people with FASD over Zoom (February 2024). We also ensured that, while people with FASD were welcome and encouraged to attend any session, specific sessions for people with FASD would be included as one of the six virtual sessions in round two, with the option for participants to speak.

Both of the small group conversations were held in English, with French translation available. These sessions were moderated by peer facilitators who guided the conversations with the panel chair, ensuring that key topics were addressed and that the perspectives of all participants were heard.

Participants were asked prompting questions focused on:

- Supports
  - What makes it easier or harder to get helpful services and supports?
  - How have these changed as you've gotten older, from when you were a kid to now?
- Prevention
  - When you talk to others about FASD, what do you tell them?
  - What do you wish people knew or understood about FASD and how to prevent it?
- Diagnosis
  - What made it easy or hard to find someone who could tell you if you have FASD?
  - What advice would you give to others who might have FASD and are trying to get a diagnosis?
- Case identification and data collection
  - What advice can you give to organizations and governments that would like to collect information on FASD in Canada?
- Strengths
  - What are some of the things that you like or appreciate about living with FASD?

During both sessions, a recorder captured detailed notes on the discussion content without identifying information. The recorder then reviewed these notes and analyzed them for emerging themes. Ultimately, six key themes were identified.

These conversations had a combined total of 27 attendees with FASD, some of whom attended both sessions. The conversations reflected a sense of community and mutual support among participants, and led to the sharing of a broad range of valuable insights and experiences.

Written surveys

We conducted two online written surveys, one for each round of engagement, primarily targeting organizations. As with the live virtual sessions, an initial round was used mainly to gather data while a second round sought feedback on preliminary findings.

Both surveys were conducted using the Alchemer online survey tool. Respondents were given the option to complete the survey questions through the survey tool itself, or, alternatively, as a downloadable document which was completed offline and submitted for integration into Alchemer. The surveys were distributed through emails sent to over 1,000 organizations, as well as through links made available during the live virtual sessions. The surveys accepted responses for a total of 25 days (round one) and 28 days (round two). Respondents could complete the survey in English or French.

Responses were collected by the Alchemer online survey tool and the auto-generated report was analysed and organised thematically. We noted in our analysis cases where multiple individuals from the same organization responded.

Across both rounds of written surveys, we received a total of 463 responses.

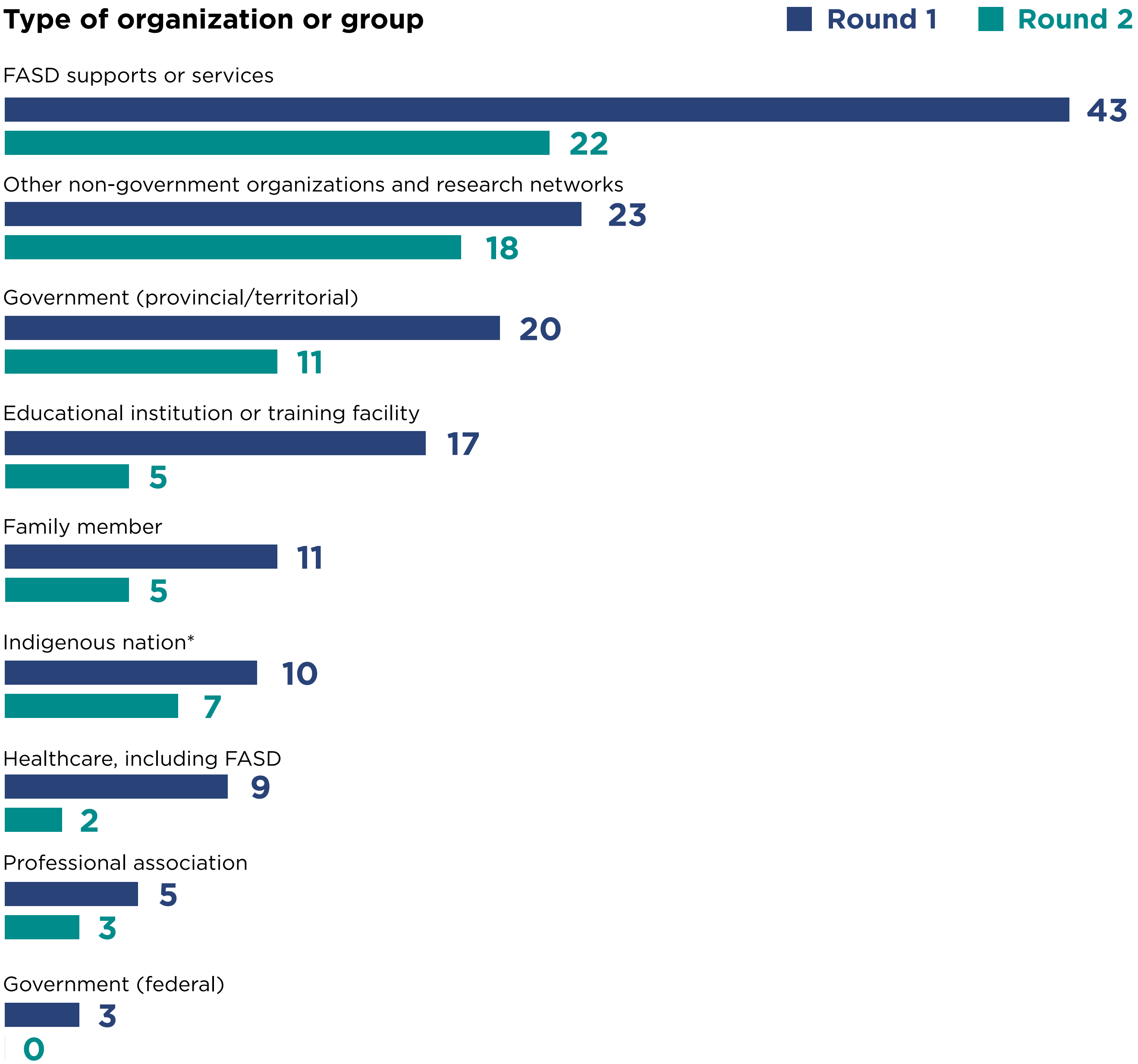
We received survey responses from nearly every province and territory. See Table 2 for geographic data, which was available for 134 respondents in round one and 66 respondents in round two. (Note that participants could select multiple locations.)

Table 2: Written survey respondents by geographic region

Geographic Region	Round 1	Round 2
British Columbia	36 (27%)	18 (27%)
Ontario	31 (23%)	6 (9%)
Alberta	23 (17%)	4 (8%)
Manitoba	7 (5%)	6 (9%)
Saskatchewan	5 (4%)	4 (6%)
Yukon	5 (4%)	5 (8%)
Quebec	5 (4%)	0
Nova Scotia	4 (3%)	1 (2%)
Northwest Territories	3 (2%)	2 (3%)
Nunavut	1 (1%)	0
New Brunswick	0	6 (9%)
Newfoundland and Labrador	0	3 (5%)
Pan-Canadian	11 (8%)	9 (14%)
International	3 (2%)	2 (3%)

A variety of organizations and groups participated in the written survey. Figure 3 summarizes the type of organization or group, where indicated by respondents. (Note that participants could identify with multiple organizations or groups.)

Figure 3: Written survey respondents by organization or group



* While 17 respondents reported affiliation with an Indigenous nation, the written surveys included a total of 53 responses from both Indigenous participants and participants affiliated with Indigenous-serving organizations

Round 1

In round one (January-February 2024), organizations and individuals involved in FASD across the country were invited to complete a survey with open-ended questions about five topics: FASD diagnosis, case identification and data collection, prevention, supports, and the 2003 Framework for Action on FASD. Across these topics, respondents were asked about current practices, key challenges and opportunities to mitigate these, promising practices, and facilitators to implementing promising work. Participants were not required to answer all questions, but instead were asked to respond to questions relevant to their organization.

Respondents were also asked to submit the top three most important policy documents they believed could help inform this assessment, as well as any additional priority documents they would like considered.

In this first round, almost 100 organizations from across Canada, in addition to many individuals, responded to the survey. Three hundred and eighty-nine respondents completed the survey, with 69 (17.7% of all responses) responding to every question, and 320 (82.3%) responding to at least one question. Respondents had a variety of backgrounds, including family members of people with FASD (e.g. parents, grandparents), clinicians (e.g. pediatricians, psychologists, social workers, speech-language pathologists), and other professionals from the education and service delivery sectors (e.g. teachers, program directors/managers, organization board members, and executive directors).

Round 2

In round two (May-June 2024), respondents were asked to provide feedback on preliminary key findings. These comprised 20 findings across 11 main themes: prevalence and prevalence data; assessment and diagnosis; stigma, acceptance, and public education; prevention; health and wellness; accessibility and community participation; education; aging and transitions; essential needs; the child welfare system; and the criminal justice system.

Round two had 74 respondents, representing 65 organizations and 9 Fellows of CAHS.

Asynchronous online discussions

An independent research and engagement firm, Environics, led two rounds of qualitative online asynchronous discussions. Each round grouped participants into one of four online communities: adults with FASD, family members providing support to people with FASD, clinicians who see people with FASD, or other professionals who work with people with FASD as part of their profession. Separate English and French communities were run concurrently.

The participants in this qualitative research were recruited from online support groups, FASD organizations, professional networks, Environics' healthcare database, and social media. Participants qualified through an online screening survey.

In each round, participants in the online community exercise were informed of the purpose of the study and the time commitment and incentive; each participant who completed the qualitative exercise was given an honorarium of $100 to thank them for their time. Participants were also provided with mental health support resources.

Discussions used the Recollective online bulletin board platform. This generated an asynchronous threaded discussion that developed as participants typed written responses to the questions. These online discussions were open for 17 days in the first round and 16 days in the second round.

Environics worked with CAHS to develop the discussion guides for each of the four groups. Experienced moderators facilitated these discussions, employing a semi-structured format to address key FASD-related topics while allowing for open discussion through an online chat function for each group. This approach ensured a safe, respectful environment for participants to share their experiences, perspectives, and suggestions in a flexible and accessible manner.

Across both rounds, a total of 183 people participated in these discussions. Twenty-two of these participants were people with FASD, almost half of whom had children. Table 3 shows a breakdown of participants by discussion group.

Table 3: Online discussion participants in each discussion group

Community	Round 1	Round 2
Adults with FASD	11 (12%)	11 (12%)
Family members providing support to people with FASD	31 (34%)	33 (36%)
Healthcare professionals who see people with FASD	25 (27%)	20 (22%)
Other professionals who work with people with FASD as part of their profession	24 (26%)	28 (30%)
TOTAL	**91**	**92**

Round 1

As in the first round of other engagement mechanisms, round one of the online discussions (January-February 2024) focused on gathering information. Participants were asked questions about diagnosis, prevention, supports, stigma, and living experience.

Round 2

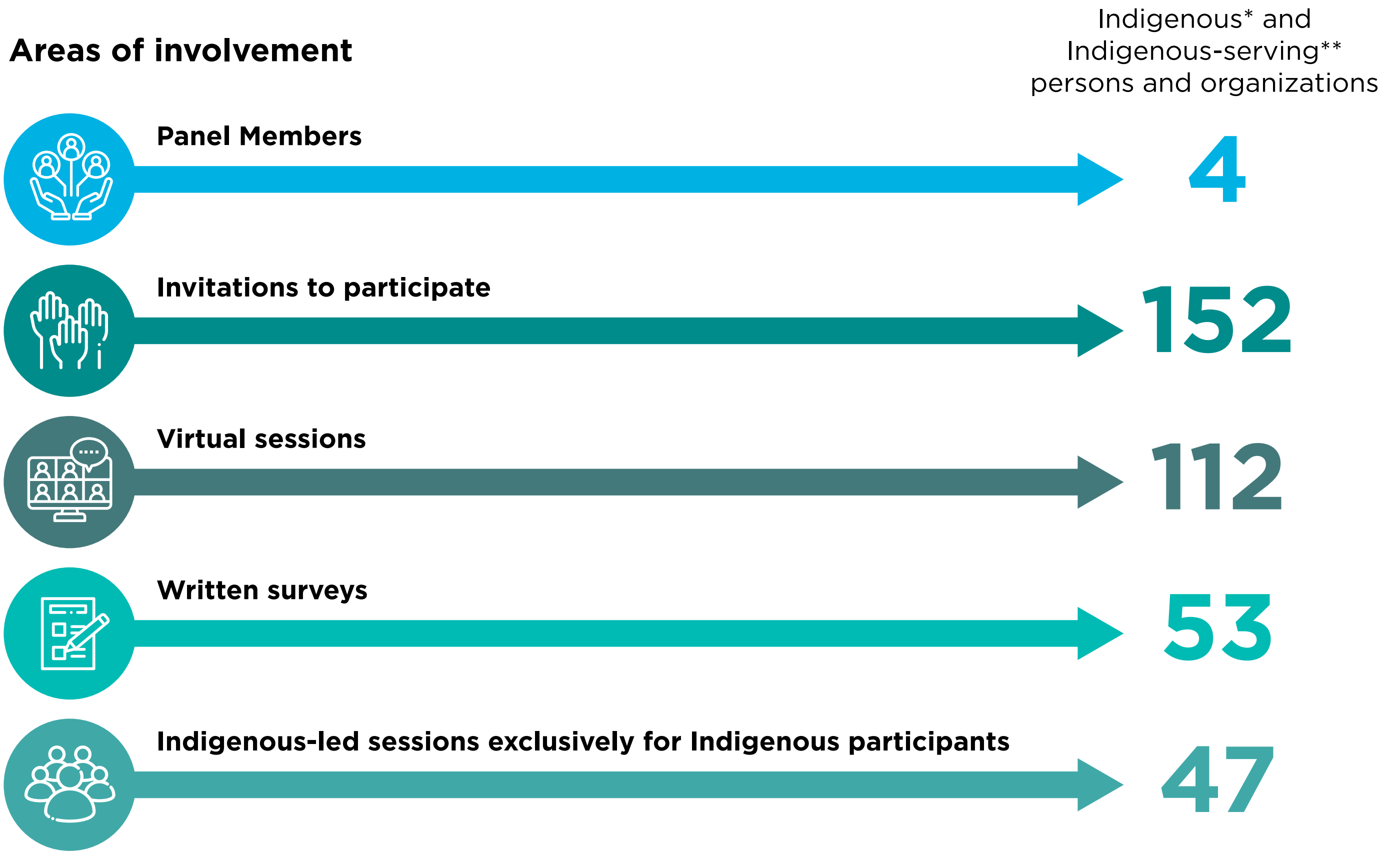
Round two (May 2024) used the same methods as round one, with one added way to engage: in addition to being able to type responses to the questions, participants had the option to record an audio response.

In round two, participants were presented with preliminary key findings, the issues that led to the key findings, and possible pathways forward. Participants were asked the extent to which they supported these key findings and the extent to which they agreed with the issues. Additionally, participants were asked to prioritize the key findings. Key findings covered prevention, diagnosis and assessment, healthcare, supports and resources, collaboration, community participation and inclusion, and the Canadian FASD Diagnostic Guidelines.

Indigenous-led engagement

Indigenous-related organizations were well represented in the general engagement mechanisms (see Figure 4 for Indigenous involvement across the assessment). There were 112 Indigenous registrants (over 11% of all registrants) across the twelve live virtual sessions open to the public, and our written survey received input from a total of 53 responses from both Indigenous participants (17) and participants affiliated with Indigenous-serving organizations (36). In addition, two Indigenous-led live virtual sessions were held specifically for Indigenous persons and organizations.

Figure 4: Indigenous participants and participants affiliated with Indigenous-serving organizations across the assessment process



* “Indigenous” is defined here as an organization or individual self-identifying in response to survey/poll questions and/or a thorough web search into the organization's leadership, history, and mission

** “Indigenous-serving” is defined here as an organization or individual that serves a large Indigenous population, has Indigenous perspectives integrated into the organization's mission and vision, and/or is strongly involved in Indigenous activities with services specifically designed for Indigenous individuals.

The two Indigenous-led live virtual sessions were designed and delivered by The Firelight Group, a 65% Indigenous-owned company with experience providing research, policy, planning, and other services for Indigenous communities and organizations across Canada. This portion of the engagement was also guided by the assessment’s Indigenous task group and hosted by this task group’s chair. These invitational sessions explored themes emerging from the assessment’s Indigenous-specific literature review and policy scan, aiming to validate and enrich findings as well as solicit perspectives and insights not captured within the literature.

From the outreach to 152 Indigenous-related organizations, 47 participants attended. These sessions adhered to a consistent format that respected cultural protocols while facilitating meaningful discussion. Participants were then presented with key findings from the literature review, setting the stage for in-depth discussions. The sessions explored promising practices in FASD programs and policies, as well as the needs and barriers faced when addressing FASD in Indigenous communities. This structure allowed for the exploration of the gaps between best practices and on-the-ground realities, helping to ensure that diverse Indigenous perspectives were captured and integrated into the assessment.

The facilitated discussions explored three broad questions:

1. Promising practices: participants reflected on key themes identified from the literature review, considering the resonance of these themes and/or contributing additional themes based on their own experiences with FASD programs, policies, and initiatives.
2. Addressing FASD in communities: Participants were asked what would be most useful for them in addressing FASD and its related issues within the communities where they live or work
3. Barriers to implementation. Participants shared the barriers to being able to implement the promising practices discussed.

Through these questions, participants reflected on the gaps between best practices and their work on the ground, identifying what needs are not being met.

During both engagement sessions, detailed notes were recorded to capture discussion content. These were then reviewed and analyzed according to the key themes within the literature, identifying where participants echoed and validated literature findings and where participants identified new themes and topics not prominently addressed in the literature.

The two sessions covered both targeted and inclusive recruitment. The first engagement session (April 2024) was a targeted, invite-only session. This invitation list was curated for diverse representation across various key categories. The second engagement session (also April 2024) included a wider audience. This event followed the same format as the targeted engagement session, except that participants split into breakout groups as the session transitioned to its discussion portion. Participants in this session were invited from an extensive distribution list comprising a wide range of Indigenous communities, health organizations, governing bodies, advocacy groups, and social service organizations from across Canada.

Government interviews

Provincial and territorial government representatives were invited to participate in small group interviews. Representatives were asked about diagnosis; case identification and data collection; prevention; supports; the 2003 Framework for Action on FASD; and organization of FASD policies, programs and services within their government. Participants were also invited to share any additional information they saw as important in Canada's response to FASD.

Through this engagement, we learned that provincial and territorial governments may not have key representatives for FASD, highlighting the complexity of addressing FASD at the policy level. Ultimately, while few provinces and territories participated in these small group interviews, provincial and territorial governments were well represented in other forms of engagement, making up at least one in ten attendees from round one of the virtual sessions, and one in five from round two.

Who participated

Key groups

The engagement process involved a broad spectrum of participants, contributing to a comprehensive and inclusive approach. Along with other representatives, we reached many groups key to understanding the challenges and opportunities related to FASD in Canada (Table 4).

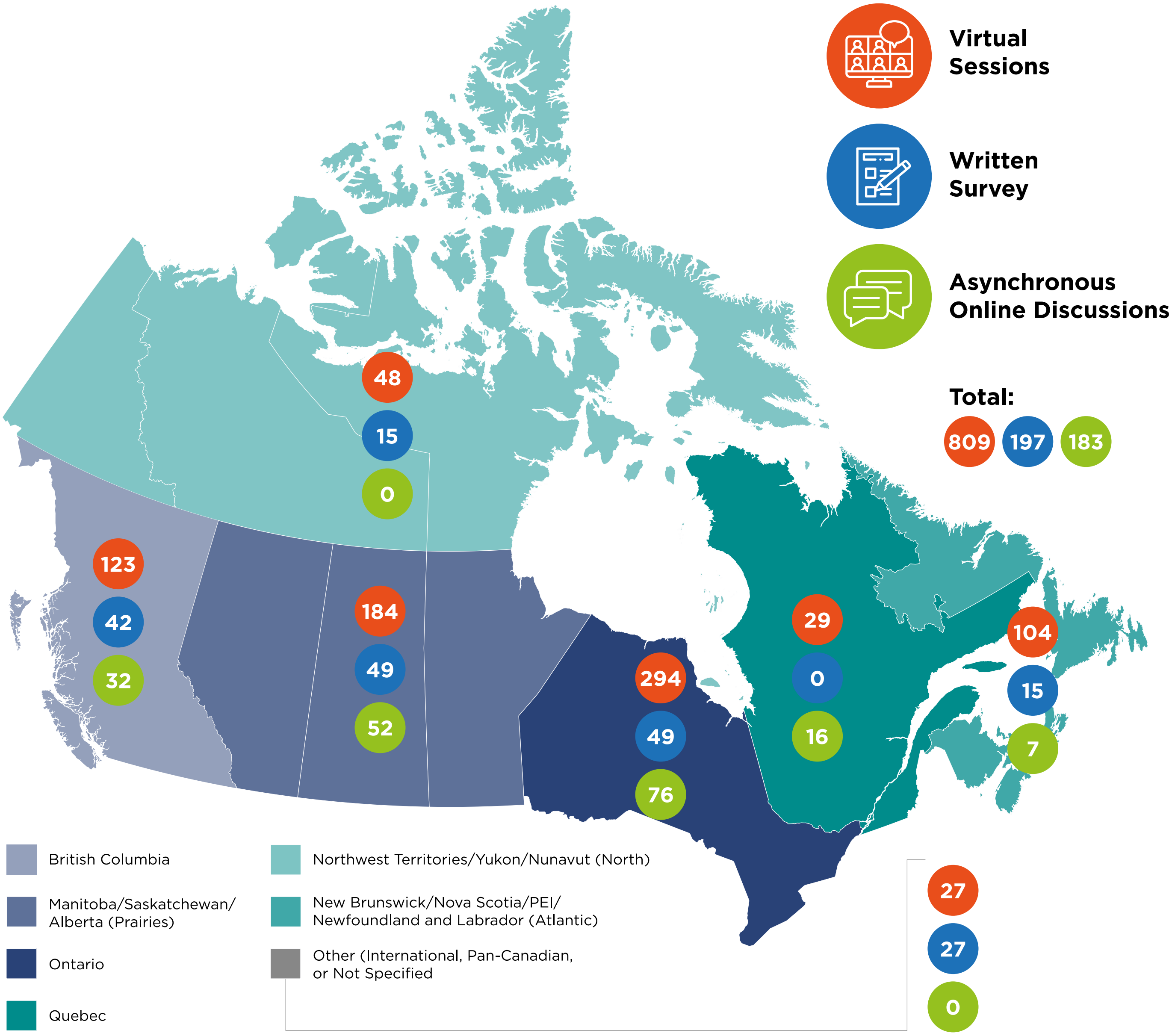
Table 4: Key groups represented in engagement

People with FASD	Adults living with FASD, providing firsthand accounts of their experiences, challenges, and needs
Family members and caregivers	Parents, grandparents, and other family members supporting people with FASD, sharing their insights on the support systems and resources required
Healthcare professionals	Physicians, nurses, allied health professionals, and other clinicians involved in the prevention of FASD, and in the diagnosis and support of people with FASD within Canada's health system
Education, service delivery, and other professionals	Teachers, justice system representatives, and members and leaders of organizations from various sectors involved in FASD prevention and in supporting individuals with FASD
Researchers and academics	Experts in the field of FASD and related research, providing insights based on their research and knowledge from peer-reviewed evidence
Policy makers and government representatives	Individuals involved in the development and implementation of policies related to FASD, contributing this perspective on systemic and policy-related challenges
Indigenous persons	Representatives from Indigenous communities and organizations, to ensure understanding of and relevance to the perspectives and needs of Indigenous communities
Non-government organizations (NGOs)	Representatives from organizations working in the field of FASD, providing insights into the practical challenges and opportunities for improving support and services

Geographic diversity

Participants joined from across Canada. Figure 5 shows a geographic breakdown of participants across different forms of engagement, where data was provided.

Figure 5: Participants across different forms of engagement by geographic region



How we used this information

Through this engagement process, we invited input on all areas of FASD we sought to understand: prevention, data collection and case identification, assessment and diagnosis, interventions and supports, and the 2003 Canadian FASD Framework for Action—as well as cross-cutting impacts/concerns.

Results from the first round of engagement sessions were examined by the panel in light of the draft literature review and policy scan material. On the basis of this, the panel then developed two sets of preliminary key findings: one based on the Indigenous-specific literature and policy reviews and engagement sessions, and one based on the general reviews and engagement.

In the second round of engagement, participants provided feedback on these preliminary key findings. This feedback, too, was synthesized and examined by the panel, and integrated into revisions of the key findings.

This strategy allowed for iterative integration of community knowledge and living experiences with FASD, complementing the information gathered from the literature review and policy scans. By structuring the engagement in this manner, the process ensured a robust and comprehensive exploration of FASD-related issues, combining multiple forms of expert input and knowledge.

In order to validate the initial analyses of data gathered across these multiple engagement mechanisms, a reviewer independently reviewed all of the comments gathered through the surveys and all virtual sessions and examined the reports from the Indigenous-led online discussion and the asynchronous online sessions in order to generate an integrated summary of what we heard. This integrated report helped inform the framing and writing of the assessment report and to incorporate comments that help to contextualize the evidence collected through the literature and policy reviews. This integrated report was organized around 11 main themes that emerged through the engagement process, with sub-themes as appropriate: characteristics and impact of FASD, stigma, inclusion, Indigenous communities' experiences and perspectives, prevalence and data collection, prevention, assessment and diagnosis, interventions, supports, the 2003 National Framework, and considerations for provincial and national frameworks. Note that detailed data and the ensuing reports are not publicly available because these intermediate documents were produced for internal use and the results needed to be interpreted in the appropriate context.

Strengths and limitations of the process

From the beginning, CAHS was committed to an engagement process that reflected the complex, multifaceted nature of FASD. Our approach valued representation, inclusivity, applicability, equity, and system thinking. These values were embedded in how we designed and delivered all engagement activities, as well as how we recruited participants.

As a result, the engagement process for the FASD assessment demonstrated significant strengths in its approach. Offering multiple engagement methods provided options for people to participate in the ways most accessible and convenient to them. This ensured broad participation across diverse groups. This inclusive approach, coupled with the collection of both qualitative and quantitative data, provided a rich, nuanced understanding of FASD-related issues.

In addition, holding multiple forms of engagement across two rounds enhanced transparency and accountability. The two rounds enabled an iterative process for developing and refining key findings based on the feedback of a broad range of participants.

While planning, designing, and delivering the different forms of engagement, we endeavoured to ensure that people with FASD were welcomed and able to participate. Wherever possible, we worked with people with FASD and their families to ensure that questions were clear and meaningful, language was respectful and person-centred, and modalities were accessible. If we learned that something was not working, we adjusted the engagement mechanisms.

Mechanisms were designed to allow for meaningful participation while also maximizing participation. For example, the asynchronous online discussions separated participants into four groups—each with a dedicated platform—to enable more open and comfortable sharing of experiences, perspectives, and suggestions. This enhanced the depth and specificity of feedback. It also fostered a nuanced understanding of the unique challenges and needs within each group, while mitigating potential concerns about judgment or misunderstanding from other groups. Further, the asynchronous format provided time for reflection and considered responses, adding to the depth and quality of the input received.

Similarly, in recognition of the distinct experiences of Indigenous communities, we grounded engagement with these groups in cultural safety through Indigenous leadership. The structure of the Indigenous-led sessions allowed for a comprehensive exploration of the gaps between best practices and on-the-ground realities, ensuring that we understood the perspectives, needs and barriers faced by Indigenous communities when addressing FASD.

The engagement process also faced limitations. Some mechanisms, like the virtual online sessions aimed to prioritize openness and accessibility, leading to large groups that made group interaction difficult. Instead, the choice was made to use the Q&A function to capture brief written responses. While this necessarily limited the interaction between participants as well as the level of detail that was possible in the brief comments, the moderator was able to pose follow-up questions to build on the responses, participants often typed reactions to each other, and the mechanism did generate a wealth of information from a large number of participants. Another limitation was that parts of the engagement were conducted in a compressed time period, which may have reduced attendees' availability for some mechanisms. In addition, many ways of engaging were qualitative in nature (collecting non-numerical data such as text or audio). This means that the results of these components provided an indication of participants' views about the issues explored, but cannot necessarily be generalized to the targeted audience segments. This is especially salient with engagement mechanisms such as the asynchronous online discussions, where the two living experience groups (people with FASD and family members) may have been subject to sample bias. The participants who were willing and able to contribute may not reflect the broader population of people with FASD. This could limit conclusions about differences among subgroups.

Related to this, the stigma of FASD means that participation could be emotionally difficult, especially for people with FASD and their families. While we worked to minimize this toll and provided resources for self-care and mental health support, building a complete picture of FASD made it necessary to discuss difficult and sometimes contentious topics. This may have presented obstacles to fuller engagement among people with FASD.

Finally, despite concerted recruitment efforts, some groups were underrepresented among engagement participants. These include Francophone participants and people in remote areas. These limitations underscore the complexity of conducting comprehensive engagement across a vast and diverse country.

Conclusion

The engagement process played a crucial role in informing the development of a comprehensive and evidence-based assessment of FASD in Canada. Engaging with key actors with knowledge and experience related to FASD provided essential context for a comprehensive understanding of FASD. The participants' input allowed us to develop key findings that take into account the perspectives of people with FASD, their families, and associated researchers and professionals. By incorporating the voices and perspectives of those directly affected by FASD, we have been able to capture insights beyond those reflected in the literature and policy documents and to develop targeted and practical pathways forward that address the key challenges and opportunities identified.

We greatly appreciate the invaluable efforts made by the participants who contributed to this engagement process.