Canada's Drug Agency
L'Agence des médicaments du Canada

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Consultation Summary From Focus Groups With First Nations, Inuit, and Métis Peoples on Proposed Pan-Canadian Guidance for Newborn Screening

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Introduction

Background

In July 2024, Canada's Drug Agency initiated a public engagement process to gather input on a discussion paper for newborn screening as part of the National Strategy for Drugs for Rare Diseases. The discussion paper includes the foundational elements that will underpin the recommendations made by the Newborn Screening Advisory Panel, such as:

- developing a proposed common set of guiding principles for newborn screening
- exploring a proposed process and criteria for adding or removing conditions
- recommending conditions for which newborn screening programs in Canada could screen.

To ensure that the unique perspectives of First Nations, Inuit, and Métis people were being captured alongside input from other people living in Canada, Canada's Drug Agency initiated work to host a series of focus group discussions with individuals from First Nations, Inuit, and Métis communities regarding the draft newborn screening guidance.

Approach

Canada's Drug Agency selected an Indigenous consultant, Kali Moss of Sage Solutions, to coordinate and facilitate the 3 distinction-based focus groups. The consultant managed the recruitment of participants (via direct invitation and social media posts), revised engagement materials, and facilitated the online focus group sessions, which took place in September 2024. A total of 21 individuals participated in the online focus groups. A validation step was included, during which all participants were given an opportunity to review a draft version of the report.

What Was Asked?

Proposed Guiding Principles

- Is the draft guiding principle "Health rights of the newborn" clear? Does it make sense? Does it resonate with you? Is there anything missing?
- Is the draft guiding principle "Equity" clear? Does it make sense? Does it resonate with you? Is there anything missing?
- Is the draft guiding principle "Effectiveness, safety, and quality" clear? Does it make sense? Does it resonate with you? Is there anything missing?
- Is the draft guiding principle "Transparency" clear? Does it make sense? Does it resonate with you? Is there anything missing?
- Is the draft guiding principle "Collaboration" clear? Does it make sense? Does it resonate with you? Is there anything missing?
- Is the draft guiding principle "Sustainability" clear? Does it make sense? Does it resonate with you? Is there anything missing?

Proposed Criteria

- When considering adding a condition to a pan-Canadian list for newborn screening: What would you like to know about the condition? Are there other questions or aspects you'd like asked or considered?
- When considering adding a condition to a pan-Canadian list for newborn screening: What would you like to know about the screening test? Are there other questions or aspects you'd like asked or considered?
- When considering adding a condition to a pan-Canadian list for newborn screening: What would you like to know about the treatment? Are there other questions or aspects you'd like asked or considered?
- When considering adding a condition to a pan-Canadian list for newborn screening: Are there other questions or aspects you'd like asked or considered?

Anticipating Emerging Conditions

- Are there other emerging conditions that you would recommend the advisory panel consider in its final report?

Input on Draft Newborn Screening Guidance

The 3 distinction-based sessions yielded the following participant input, summarized for readability, and organized by focus group and query.

First Nations Focus Group

Feedback on Guiding Principles

Health Rights of the Newborn

Several participants emphasized that this guiding principle could be expanded to consider a broader understanding of health and should include not only physical health but also mental, emotional, and spiritual well-being. One participant shared a personal experience, describing the emotional and mental toll that a false-positive screening result had on their newborn and family. They felt that the emotional and spiritual health of the baby was not being adequately considered, especially when hospital staff seemed dismissive of their concerns. This participant also advocated for clearer definitions in the principle — specifically what types of health are being prioritized, and whether they include emotional, mental, and spiritual aspects, which are crucial to the holistic well-being of a newborn.

Another key suggestion was the inclusion of cultural sensitivity for Indigenous families who often integrate traditional medicines and spiritual practices into their care. Participants described a need for health care professionals to be more respectful and understanding of these practices, particularly in clinical settings like neonatal intensive care units (NICUs) where Indigenous cultural practices may be unfamiliar to staff.

While some participants found the principle to be clear and well-structured, others pointed out that focusing on all aspects of health (emotional, spiritual, mental, and physical) could create challenges for a medical agency that might not be equipped or willing to address those dimensions. They suggested that the agency be careful to clarify what aspects of health it is responsible for because this could expand its scope significantly.

Additionally, participants called for equitable access to screening for all newborns and stressed the importance of involving parents in decision-making, especially regarding the follow-up procedures after screening. Some also mentioned the need for ongoing evaluation of the screening practices to ensure they remain relevant and effective. Informed choice, transparency, and considering the broader context of family wellness were seen as essential to providing comprehensive care for newborns.

Equity

Participants raised several points for improvement under this guiding principle. Many felt that, although the principle successfully emphasizes the importance of ensuring equitable access to quality screening and follow-up care for all newborns, it lacks concrete details on how these goals would be achieved in practice. The phrase “diverse needs and circumstances” was considered vague by some participants who suggested that it would benefit from specific examples to clarify how equity would be applied in different contexts.

Several participants expressed concerns about the subjectivity in phrases like “follow-up where appropriate,” arguing that such language could leave critical decisions to an individual health care provider’s judgment. They believed that some serious conditions should always be followed up on, regardless of the provider’s opinion. Participants shared their personal experiences of feeling overwhelmed by information about their child’s possible condition, which was later determined to be a false-positive. These experiences led them to suggest that clearer guidelines for follow-up care are needed, particularly to avoid unnecessary stress on families.

Participants also highlighted the need to consider how equity might be applied differently in rural and remote communities, particularly for Indigenous populations. One participant felt that the screening process sometimes seemed biased, with assumptions made based on their cultural background or geographic location. They questioned whether newborn screening was tailored differently for certain populations and called for greater cultural sensitivity in how these processes are implemented.

While most agreed that the principle was clear and resonated with them, some participants recommended expanding the focus to include not only the best interests of the newborn but also the family unit. They pointed out that additional testing and follow-up care can disrupt family life, especially in communities where health care access is limited. Balancing the wellness of both the newborn and the family should be a priority in making care decisions.

Effectiveness, Safety, and Quality

Participants generally agreed that the draft guiding principle “Effectiveness, safety, and quality” is clear, well-structured, and resonated with them. However, they felt that there are a few important areas where the principle could be strengthened or clarified.

Participants suggested that ethical considerations should be explicitly included in this guiding principle. While the focus on safety and quality is appreciated, they felt that acknowledging the ethical implications of screening and follow-up care, especially when it comes to handling sensitive or potentially life-changing information for families, is critical.

There was also a request for more detail on what constitutes “high quality” in the context of newborn screening. Participants felt that this concept could benefit from further explanation — whether it refers to the sensitivity and specificity of tests, the ease of use, or other factors. Defining what makes screening effective and high-quality could provide clearer guidance for health care providers.

Another suggestion was to clarify where the newborn screening pathway begins and ends, ensuring there is a clear understanding of what constitutes the full scope of care — from initial testing through to final diagnosis and follow-up care. Some participants wondered whether certain populations, such as First Nations newborns, are under-screened due to disparities in access to health care. They highlighted the importance of collecting and analyzing data on this topic to better understand whether specific groups are receiving equitable access to screening.

Participants shared personal experiences of how the screening program helped detect life-threatening conditions in family members, and they emphasized the value of this program. However, they also called for more data collection to back up the anecdotal evidence and to ensure that the principle is rooted in evidence-informed practices that address health care disparities.

The principle’s focus on continuous improvement was well-received, and participants agreed that ongoing evaluation and refinement of screening practices are essential for maintaining safety and quality. However, some participants noted that a more inclusive approach could be achieved by involving a wider range of interested parties, including parents, health care providers, and community organizations, in decision-making processes. This could help ensure that screening programs are designed to meet the needs of diverse populations and are accessible to all.

Transparency

Participants indicated that the draft guiding principle “Transparency” is clear and well-crafted overall. The principle resonated with them, but several participants emphasized the importance of ensuring that information is accessible to all. They suggested that transparency should be about not only providing clear and accurate information but also ensuring that the information is presented in multiple formats to accommodate different needs.

For example, participants recommended that information be available in both written and video formats, which can help overcome literacy barriers. Additionally, they proposed that materials be available in Indigenous languages, especially in regions where such languages are commonly spoken. This would help ensure that parents and caregivers can fully understand the information being shared, which is critical to building trust and ensuring equitable access to newborn screening services.

Collaboration

Participants appreciated the focus on involving diverse perspectives in the development of newborn screening policies, processes, and procedures. By emphasizing collaboration, the principle acknowledges that drawing from various experiences and viewpoints can lead to more inclusive and effective health care approaches.

However, several participants raised questions about the use of the term “partners.” They felt that the term should be more clearly defined, with 1 participant asking if it encompasses all sectors involved in the process. Clarification was provided during the discussion, with 1 moderator explaining that the term “partners” refers to anyone with an interest in the work, including people with lived experience, not just professionals or organizations. Participants appreciated this explanation and the effort to include a wide range of voices, but they still felt that the definition of “partners” should be clearer in the principle itself.

Overall, the principle was viewed positively, with participants commending its inclusivity. However, they recommended that the final document explicitly define the term “partners” to ensure that all relevant perspectives, including those of individuals without formal expertise but with valuable lived experience, are adequately represented.

Sustainability

Participants found the draft guiding principle “Sustainability” to be clear and easy to understand. There were no significant concerns or suggestions for improvement raised during the discussion.

Feedback on Proposed Criteria

Condition

When considering adding a condition to a pan-Canadian list for newborn screening, participants felt that it would be important to also understand the effects of the condition on the family. In addition to the medical aspects of the condition, participants suggested considering how managing the condition could impact the family unit, including emotional, financial, and logistical challenges. Including these broader implications would provide a more comprehensive understanding of the condition’s impact and could help shape support systems around the families of affected newborns.

Test

When considering adding a condition to a pan-Canadian list for newborn screening, participants highlighted several key questions about the screening test. These include:

- Ease of administration: Can the test be easily administered shortly after birth? What sample type is required (e.g., blood, urine), and how much of it is needed?
- Informed consent: Participants emphasized the importance of obtaining informed consent from families before the test is conducted. Families should be properly informed about the purpose and process of the screening.
- Accessibility of the test and treatment: Is the diagnostic test, and any subsequent treatment, accessible to all populations, especially those in rural or remote areas?

- Risks and side effects: Are there any risks or side effects associated with the test? Is it noninvasive or minimally invasive to ensure the least amount of discomfort for the newborn?

Treatment

When considering adding a condition to a pan-Canadian list for newborn screening, participants identified several important questions regarding the treatment:

- Health insurance coverage: Is the treatment fully covered by public health insurance, ensuring that families do not face financial barriers to care?
- Treatment specifics: What does the treatment involve, and how long will it take? Participants wanted to know the full scope of the treatment process, including its duration and intensity.
- Accessibility: Is the treatment available within the family’s community, or would travel be required? Accessibility to treatment in remote or rural areas is a critical consideration.
- Follow-up care: Participants emphasized the importance of follow-up care to ensure ongoing support after the initial treatment.
- Risks and side effects: Are there risks of complications or side effects associated with the treatment, and how are these managed?
- Peer support: Is there peer support available for families who have undergone this treatment, providing them with emotional and practical guidance?

Other Considerations

When considering adding a condition to a pan-Canadian list for newborn screening, participants suggested that an additional important aspect to consider is the financial burden on families. They emphasized the need to assess the costs families might incur while pursuing diagnostic testing or treatment, including travel expenses, out-of-pocket costs, and lost income. Understanding the financial impact is crucial to ensure that families are not placed under undue economic strain while seeking necessary care for their newborns.

Anticipating Emerging Conditions

Participants recommended several emerging conditions that they believe the advisory panel should consider including in its final report. These conditions include:

- antithrombin III deficiency
- cystic fibrosis
- hip dysplasia
- long QT syndrome.

Métis Focus Group

Feedback on Guiding Principles

Health Rights of the Newborn

Participants responded positively to the draft guiding principle “Health rights of the newborn.” They appreciated that the principle centres the newborn as the individual most affected by the screening and related health procedures. One participant, a mother of twins, expressed appreciation for the focus on the baby, emphasizing that the health information belongs to the newborn, making the principle personally meaningful. Another participant suggested that a holistic approach to care could be considered, though they did not elaborate on this point.

Equity

Participants raised concerns about the guiding principle's practical application, particularly in terms of accessibility.

One participant shared their experience living in a rural area, where the accessibility of newborn screening and redraw services can be limited. They pointed out that many families face significant financial and logistical burdens when required to travel to clinics because there are only a few places offering these services. Additionally, they suggested that health care providers, including doctors, are not always aware of available options (or lack thereof), which adds further challenges.

This participant recommended that the guidance address the accessibility of testing locations and ensure the quality of procedures, such as encouraging best practices for managing newborn pain (e.g., skin-to-skin contact or sucrose gel during testing). Another participant added that the principle should also consider the best interests of both the family and the newborn, highlighting the importance of family-centred care.

Effectiveness, Safety, and Quality

Participants generally found the draft guiding principle "Effectiveness, safety, and quality" to be clear and appreciated its focus on regular review and evaluation. However, 1 participant felt that follow-up care was missing from the principle. They emphasized the importance of including follow-up care in the discussion of effectiveness because this ensures that families receive proper support after the initial screening, particularly when managing conditions identified through the screening process.

Transparency

Participants suggested a few key areas for improvement. Several participants emphasized the importance of ensuring that information is available in multiple languages, including Indigenous languages, to ensure inclusivity. They also recommended providing information in different formats — such as videos or oral explanations — to accommodate varying literacy levels and ensure that all families can fully understand the information being shared.

In addition, 1 participant highlighted the need for the principle to explicitly address confidentiality and privacy concerns. They felt that these aspects should be considered as part of transparent communication with families, particularly when dealing with sensitive health information.

Collaboration

Participants generally agreed that the draft guiding principle "Collaboration" was good and resonated with them, particularly in its focus on involving diverse perspectives. However, 1 participant felt that the principle was vague when it came to specifying the kinds of groups involved. They expressed concern that the term "variety" could result in too narrow a representation, potentially missing key demographic groups. To avoid this, they suggested being more explicit about which groups should be included, ensuring that the collaboration process reflects a broad and inclusive range of voices across Canada.

Sustainability

One participant emphasized that newborn screening not only improves individual health outcomes but also represents a significant cost-saving measure for people living in Canada, as early detection of serious conditions can prevent complications and reduce long-term health care expenses. The participant also appreciated the inclusion of the environmental aspect, highlighting its relevance to sustainable health care practices.

Feedback on Proposed Criteria

Condition

When considering adding a condition to a pan-Canadian list for newborn screening, participants identified several key questions they would like addressed:

- Reliability and validation of the test: Is there a reliable and validated test available to accurately identify the condition in newborns?
- Risk and predisposing factors: Are there known risk factors or predisposing factors for the condition, and can the condition be prevented through early intervention?
- Severity of the condition: How severe is the condition, and what are the potential health outcomes if left untreated? Understanding the impact of the condition is crucial to determining its inclusion on the screening list.

Test

When considering adding a condition to a pan-Canadian list for newborn screening, participants expressed interest in knowing whether the screening test is invasive or noninvasive. Understanding the level of invasiveness is important to ensure the prioritization of the safety and comfort of newborns.

Treatment

When considering adding a condition to a pan-Canadian list for newborn screening, participants highlighted several important questions about the treatment:

- Effectiveness: Is there an effective treatment available for the condition?
- Duration: How long does the treatment take, and what is the commitment required for families?
- Side effects: What are the potential side effects or adverse reactions associated with the treatment?
- Variability in response: Do different newborns respond to the treatment differently based on factors like genotype, severity of the condition, or the age at which treatment begins?
- Accessibility in Canada: Is the treatment something that can be effectively provided within Canada, and is it accessible to families across the country, including in rural or remote areas?

Other Considerations

Participants did not raise any additional points for consideration.

Anticipating Emerging Conditions

Participants recommended several emerging conditions that they believe the advisory panel should consider in its final report. These conditions include:

- phenylketonuria (PKU)
- cystic fibrosis
- sickle cell disease.

Inuit Focus Group

Feedback on Guiding Principles

Health Rights of the Newborn

Participants acknowledged the importance of the draft guiding principle “Health Rights of the Newborn,” but they emphasized that systemic barriers and jurisdictional issues disproportionately affect Inuit families. One participant highlighted significant challenges that Inuit face, particularly those who are medically relocated to urban centres like Winnipeg for care. They described difficulties in accessing health services, such as the delay in obtaining a Manitoba Health card and the lack of awareness within the health care system about Inuit territorial cards as valid identification. They felt that health care systems have yet to properly address how screening should be conducted for Inuit newborns, and they called for more research and tailored processes to address the unique needs of Inuit families.

Equity

While the draft guiding principle “Equity” is clear on paper, participants highlighted significant gaps between the principle and its real-world application, particularly for Inuit families. One participant emphasized the pervasive racism and discrimination faced by Indigenous families, particularly Inuit, within the health care system. They shared that language barriers often exacerbate this discrimination, as most health care professionals are only fluent in English or French, which prevents the creation of effective therapeutic relationships. This can lead to misunderstandings, inadequate care, and a lack of appropriate follow-up after newborn screenings.

Participants also pointed out that Inuit mothers are often required to travel from the North to urban centres to give birth, where they experience poor quality of care due to racial biases. They shared stories of being dismissed and of health care workers’ stereotypes about Inuit such as that they live in overcrowded conditions or use drugs and alcohol during pregnancy. These experiences contribute to feelings of being marginalized and unheard within the health care system.

The participants expressed frustration that the principle of equity, as written, does not reflect the reality of how Inuit are treated. They called for clearer communication between health care professionals and families, as well as tangible actions to address systemic racism and ensure that Inuit families receive the equitable care promised in the guiding principle. Several participants stressed that equity requires more than just words on paper; it must be reflected in actions and outcomes within the health care system.

Effectiveness, Safety, and Quality

One participant pointed out that while the principle seems effective on paper, it does not always reflect the reality of care provided to Inuit families. They stressed the importance of ensuring that the guiding principles take into account Inuit ecological knowledge and values, which are often overlooked in health care practices. The participant emphasized that Inuit world views need to be incorporated into health care to make the guiding principles truly effective for Inuit communities.

Additionally, participants highlighted the language barriers and cultural differences that often prevent Inuit families from receiving high-quality, effective care. They felt that health care providers frequently lack understanding of the cultural nuances and lived experiences of Inuit, which affects the quality of care. One participant suggested that true effectiveness and safety can only be achieved when the lived experiences of Inuit are reflected in health care practices and policies.

Another participant shared their worry that the health care system may not be fully addressing the complexity of newborn care for Inuit families.

Participants also recommended that the advisory panel reflect the diversity of the populations being served, suggesting that Inuit representatives be included at decision-making tables alongside First Nations and Métis voices.

Transparency

Participants emphasized that, while the principle is clear and makes sense in theory, the reality is quite different, especially for Inuit families who must relocate for medical care. One participant shared a powerful example of an Inuit mother who had to move from the North to the South for her child’s medical treatments. Despite receiving the necessary care, there were major financial and logistical challenges due to a lack of support systems. Families in these situations often find themselves without income, relying on child tax benefits to manage transportation and basic needs. This disconnect between the northern and southern health care systems, and the jurisdictional issues between provinces and territories, leaves many Inuit families struggling to access resources, such as housing and financial aid, during long-term medical stays.

The participant explained that these systemic issues have led to profound consequences, such as the involvement of the child welfare system, with children being apprehended because their parents could not provide access to adequate health care due to lack of support. They stressed that this kind of systemic failure creates additional injustices for Inuit families, compounding the already difficult situation of being far from home and without resources.

Collaboration

Participants expressed serious concerns about how collaboration is currently implemented in practice. One participant shared that Inuit families seeking screening or medical services for their children in Nunavut are often not taken seriously by health care providers. They explained that health care workers sometimes assume that Inuit families request screenings to secure a “free trip to the South” rather than genuinely needing medical care. This racism and discrimination have led to devastating outcomes, with many Inuit babies and family members dying due to the lack of proper medical attention.

The participant stressed the importance of meaningful collaboration between Indigenous families and health care providers, which requires eliminating these harmful assumptions and biases. While the recent apology from the Canadian Medical Association for medical harms to Indigenous Peoples is a positive step, participants emphasized that real change will only happen when the voices and perspectives of Indigenous communities are heard and respected in the health care system. They expressed hope that focus groups like these can help bring about those positive changes by fostering genuine collaboration and addressing these systemic issues.

Sustainability

While the principle makes sense and resonated with the participants, they pointed out that the current system does not reflect the sustainability outlined in the document. This suggests a gap between the ideal vision of sustainability in health care practices and the actual conditions faced by families, particularly Inuit families, in accessing consistent and long-term health care support.

Feedback on Proposed Criteria

Condition

When considering adding a condition to a pan-Canadian list for newborn screening, participants would like to know whether the condition is hereditary and can be passed down through families. Understanding the genetic or hereditary nature of the condition is important for families because it could affect not only the newborn but also other family members and future generations.

Test

When considering adding a condition to a pan-Canadian list for newborn screening, participants emphasized the importance of receiving clear test results, regardless of whether they are positive or negative. They expressed a desire to know the next steps in the process if the test results are positive or negative, ensuring families understand what the results mean and how to proceed. Additionally, participants would like to know what conditions or factors can be ruled out based on the test results, which would provide clarity on what the screening has determined.

Treatment

When considering adding a condition to a pan-Canadian list for newborn screening, participants indicated that they would like to know several key details about the treatment:

- Side effects: What are the potential side effects, both immediate and long-term, of the treatment?
- Purpose of the treatment: What is the treatment intended to address or heal? Participants want to understand the specific outcomes or benefits of the treatment.
- Type of treatment: Is the treatment primarily medication-based, or does it involve frequent doctor visits and ongoing care?
- Location of treatment: Will the treatment be available in the newborn’s home community, or will families need to travel to larger medical centres, possibly requiring long-distance trips?

Other Considerations

When considering adding a condition to a pan-Canadian list for newborn screening, participants highlighted several additional questions and concerns:

- Hereditary testing: If the condition is hereditary, should other family members be tested to determine if they also have the condition? This would allow for a more comprehensive approach to managing inherited conditions within families.
- Support for families: Participants raised concerns about the logistical and financial challenges faced by families, particularly Indigenous families from remote communities, when their newborn is in the NICU. One participant shared a story about a family unable to visit their baby in the NICU because they could not get the necessary documentation to receive financial assistance. They emphasized that support systems should include someone to help families navigate these processes, ensuring they have the resources to care for their newborn.
- Impact on family life: Screening and treatment for certain conditions can disrupt the daily life of families, especially if parents have to manage care for other children while navigating treatment for their newborn. Participants wanted to ensure that these potential disruptions are considered when adding a condition to the screening list.
- Cultural sensitivity in care: Participants also stressed the importance of asking parents for permission and involving them in decisions about their baby's treatment. They shared examples of situations where medical procedures were performed without consulting the parents, leaving them feeling disempowered. Ensuring that parents, especially Indigenous parents, are comfortable with the treatment decisions is critical for providing respectful and inclusive care.

Anticipating Emerging Conditions

A participant suggested that internal hernia be considered as an emerging condition for inclusion in the advisory panel's final report on newborn screening.

General Overarching Themes

Systemic Barriers and Inequities

- **Geographic and jurisdictional disparities**: Participants, especially those from Inuit and rural communities, highlighted the systemic barriers they face in accessing health care services, particularly the challenges of travelling long distances and dealing with interjurisdictional issues between northern and southern health systems. For example, delays in receiving health cards and logistical challenges related to long-term medical stays significantly hinder access to care.
- **Financial and logistical support**: Families relocating for medical care often lack financial resources and support, making it difficult to afford travel or housing. This is exacerbated by the lack of coordination between social services and medical providers, especially when documentation and assistance are needed.

Cultural Sensitivity and Respect

- **Cultural humility in care**: Participants repeatedly stressed the need for culturally sensitive care that recognizes Indigenous values, practices, and world views. They shared instances where they felt dismissed or disempowered by health care providers who did not consider their cultural preferences or ask for their input, such as being ignored when it came to feeding decisions or the use of traditional medicines.
- **Racism and discrimination**: Many participants described facing racism and discrimination in health care settings, where their requests for care were not taken seriously. This leads to mistrust in the system and contributes to negative health outcomes for Indigenous families.

Communication and Accessibility

- **Language barriers**: Language barriers were frequently mentioned as a major obstacle for Inuit families accessing health care. Participants stressed the importance of providing information in Indigenous languages and ensuring that health care professionals communicate clearly with families, especially when discussing newborn screening and treatment options.
- **Clear communication of screening results and next steps**: Participants wanted transparency in the results of newborn screenings, even when tests come back negative, so they can understand what has been ruled out and what steps to take next. They emphasized the need for accessible and clear communication from health care providers.

Equity in Health Care Access

- **Consistent and equitable care**: Participants called for equity in accessing newborn screening, regardless of geography, socioeconomic status, or ethnicity. They raised concerns about the unequal access to follow-up care and the subjectivity of certain medical decisions, which can lead to disparities in how care is administered.
- **Family-centred care**: Equity, as highlighted by participants, must extend beyond the newborn to the entire family unit. Participants emphasized the need to balance the well-being of the family with the care of the newborn, acknowledging the disruptive impact that medical treatments can have on family life.

Follow-Up Care and Treatment

- **Importance of follow-up**: Participants pointed out that follow-up care is often missing or inconsistent, especially for families in remote areas. They stressed the importance of ensuring that families receive proper follow-up care and ongoing support after screenings.
- **Access to treatment**: The ability to access treatment within local communities, without the need for frequent travel, was a significant concern. Participants wanted more clarity on the availability and logistics of treatment, especially for conditions that may require long-term care.

Family Involvement and Consent

- **Informed consent and family involvement**: Participants repeatedly emphasized the importance of involving families in decision-making processes, especially regarding treatment options for newborns. They expressed concerns about health care providers making decisions without consulting parents, which has made families feel powerless. Participants called for more respect for parental consent and involvement.

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