Community Brief

# Unpacking Priority Area #3 of Canada's Autism Strategy - Data Collection, Public Health Surveillance & Research

What we heard from the 11th annual Canadian Autism Leadership Summit participants.

This brief was created following Autism Alliance of Canada's 11th annual Canadian Autism Leadership Summit. It summarizes key ideas and reflections shared by attendees during World Café discussions after a panel presentation on *Data Collection, Public Health, Surveillance & Research*.

## How you can use this brief

### As a Policymaker

This brief offers valuable community perspectives on data collection, public health surveillance, and research. Whether you're working at the federal or provincial level, these insights can help inform policies and programs that support a more effective and coordinated approach to research across Canada.

### As a Researcher

This brief highlights gaps and community-identified needs related to improving data collection, public health surveillance, and research. It can help spark new research questions and guide studies that support meaningful real-world improvements.

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### As a Community Leader

This brief can spark local conversations and provide context for national efforts on data collection, public health surveillance, and research - so you can bring your community's perspectives to the national conversation.

### As an Advocate

This brief can help you engage with policymakers and other advocates in your region. It offers a starting point for conversations about building a national approach to data collection, public health surveillance, and research.

## Panel and World Café Engagement

The panelists began by discussing the state of autism research in Canada and how autism is currently tracked in public health. They highlighted where improvements and investments could strengthen data collection and support research that better serves Autistic people and their families. Attendees then reflected on these ideas during World Cafe discussions and shared their insights. Key points and quotes are summarized below.

Panelists: Dr. Stelios Georgiades, Dr. Evdokia Anagnostou, Dr. Melanie Penner, Dr. Mackenzie Salt, Dr. Deepa Singal

## What we heard: reflections from attendees

1. **Canada needs consistent federal and provincial/territorial data collection frameworks that are transparent, coordinated, and aligned across disciplines.** Siloed research practices and varying data standards between regions and fields limit the ability to understand and serve Autistic people and their families effectively.
2. **A clear and shared understanding of what constitutes "data" is needed to strengthen communication and public trust.** Uncertainty around how data is defined or used weakens engagement and makes it difficult to evaluate findings such as prevalence increases or diagnostic trends.
3. **Autistic people, caregivers, and Indigenous communities should co-lead data and research efforts.** Co-creation at all stages - including setting research

questions, collecting data, and sharing results - ensures relevance, respect, and equity. Compensating and acknowledging lived experience is necessary.

> *"We need to ask the community what they want to have tracked, what they want studied or documented—don't decide that for them."*

### *Box 1.* Supporting Evidence from the Canadian Academy of Health Sciences (CAHS) Autism Report, from *Research* (p. 267)

"Future autism research would benefit from:
Recruiting Autistic collaborators and research participants that reflect the diversity and intersectionality of autism."

4. **The First Nations principles of Ownership, Control, Access, and Possession (OCAP) should shape all data practices with Indigenous communities.** Storytelling and community-driven methods are recognized as valid data by many Indigenous peoples.

> *"Data needs to be culturally sensitive, community responsive, and diverse in how it is attained, including through lived experience via storytelling."*

> *"Indigenous communities have conducted their own research, but it wasn't accepted because it wasn't produced by a designated researcher. We need better, respectful ways to collect data that fit First Nations realities."*

5. **Administrative barriers, unclear research processes, and repetitive outreach discourage participation and undermine the quality of data.** Action is needed to reduce survey fatigue, streamline ethics and approvals, and ensure coordination among researchers to avoid duplicating efforts.

## Taking action on this priority

Here are some clear steps that policymakers, service providers, researchers, and community leaders can take based on what attendees shared with us.

1. **Strengthen data infrastructure and governance through coordinated frameworks and ethical sharing protocols.** Invest in secure data infrastructure and establish national legislation and agreements to support ethical data sharing across sectors, including universities, healthcare systems, and governments.
2. **Promote knowledge mobilization and shared definitions to ensure clarity and usefulness of data.** Launch a national repository of operational definitions and best practices to support consistent interpretation and application of data across research and service contexts.
3. **Scale up participatory, Autistic-led and neurodiversity-affirming research approaches.** Increase funding and visibility for research on Autistic Ways of Being and prioritize participatory projects co-designed and led by Autistic researchers.
4. **Encourage family and caregiver inclusion at all research stages through accessible training and collaboration.** Expand existing engagement in research programs and ensure compensation and recognition for family members and caregivers.

## Gaps that need attention

During the discussions, participants raised important issues that are often overlooked in policy and practice. By highlighting these gaps, we can include a broader range of voices and better address the diverse needs of our community.

1. **Greater inclusion of diverse Autistic voices, especially underrepresented groups.** Data must better reflect intersectional identities, including race, language (e.g., French-speaking communities), support needs, and lived experiences beyond those most commonly represented.

2. **Clear communication and translation of research findings to the broader public.** Research findings should be communicated in clear, accessible ways to Autistic people and families, along with education on how data is collected and why standards matter.

> *“Too often, people are blocked by research because they don’t know what the impact is or how it’s used - we need to make sure results are simplified and shared with parents and Autistic people.”*

3. **Need for consistent, disaggregated, and community-driven data collection.** Ensure data collection captures racial identity, linguistic diversity, and other demographics, with systems to identify whose voices are missing.

> *“There needs to be a mechanism to catch whose voice is missing, and ensure the data we have is actually representative of the community.”*

4. **Support for data sovereignty and recognition of First Nations-led data efforts.** Respect and accept Indigenous-led research and data practices without imposing external validation standards.
5. **Improve implementation and accountability structures.** Create a national framework with clear roles and follow-through to ensure research translates into tangible outcomes for communities.

### *Box 2.* Supporting Evidence from the CAHS Autism Report, from ***Research*** (p. 267)

“Future autism research would benefit from: Translational efforts that accelerate the pathways from discovery to impact.”

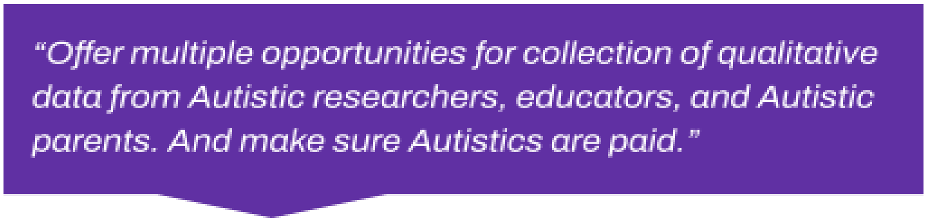
## The National Autism Network: Engaging Community for Impact

Attendees shared ideas on how the new Network can meaningfully involve autistic people, families, and communities to advance this priority through trust, collaboration, and shared action.

1. **Ensure Autistic-led and neurodiversity-affirming approaches guide all engagement efforts.** Support Autistic people and caregivers in their roles as academic researchers or non-academic research partners through funding, leadership opportunities, and the prioritization of human rights-based, neuro-affirming research.
2. **Create inclusive, community-driven advisory committees to direct data priorities.** Establish diverse advisory groups with lived experience to co-determine what data should be collected and how findings should be shared with communities.
3. **Provide meaningful compensation and remove barriers for Autistic participants and co-researchers.** Embed automatic payment structures for all Autistic contributors in research, including co-researchers and survey respondents.

### *Box 3.* Supporting Evidence from the CAHS Autism Report, from *Research* (p. 267)

"Sustained investment in training and career development opportunities can support the cultivation of the next generation of Canadian researchers prepared to address these critical research priorities. This includes funding and supporting the training and mentorship advancement of Autistic researchers."



*"Offer multiple opportunities for collection of qualitative data from Autistic researchers, educators, and Autistic parents. And make sure Autistics are paid."*

4. **Broaden outreach and engagement beyond major organizations.** Actively engage smaller, local organizations to ensure wide representation and accessibility in research activities.
5. **Use qualitative methods and accessible formats to empower participants.** Offer various ways for community members to participate in data collection, prioritizing storytelling and other qualitative approaches that reflect real-life experiences.

## Acknowledgements

We are deeply grateful to all the Summit attendees who generously shared their time, experiences, and insights. Your contributions are at the heart of our work and continue to shape the path toward more inclusive and responsive autism policies in Canada.

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