09 h 35 - 10 h 55

Panel: Labour and employment

Strong evidence for labour market policy requires bringing together very timely data from a variety of sources. This panel will focus on the ways stakeholders need to work together to address data ga...

View More

11 h 00 - 12 h 20

Panel: Health

This panel will discuss challenges facing researchers and the policy community working in health as they navigate the multi-jurisdictional health research landscape in Canada. The panel includes Sylvana Côté (University of Montreal), Laura Duncan (McMaster University), and Kim McGrail (University of British Columbia).

View Less

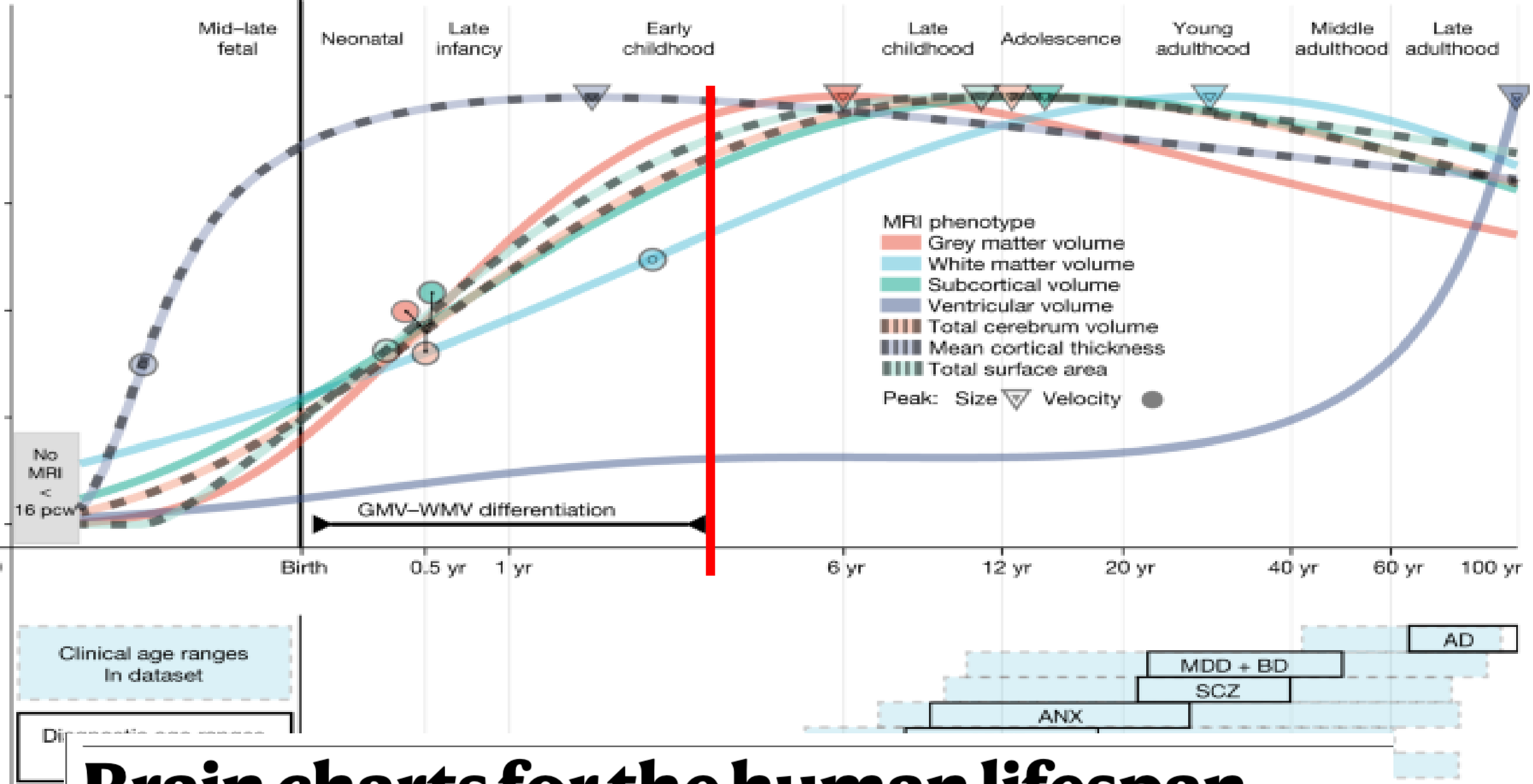
12 h 20 - 13 h 00

Lunch

Lunch will be provided. Please contact the event organizer with any dietary restrictions and we will try to accommodate.

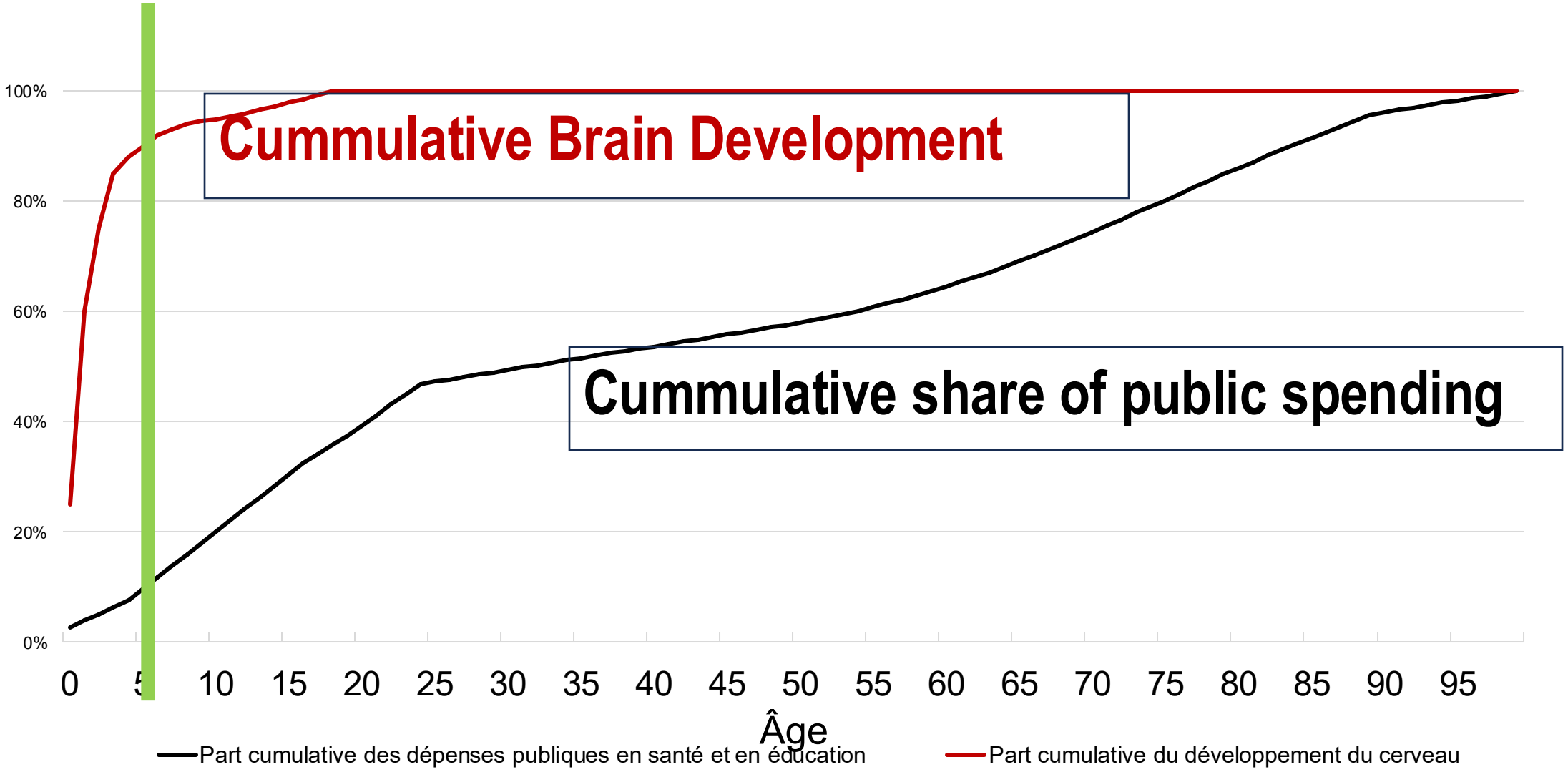
Why do we need population-based, pan canadian data to improve children's health and education?

Sylvana Côté
Public Health U of Montreal



Brain charts for the human lifespan

Guide public spending investments

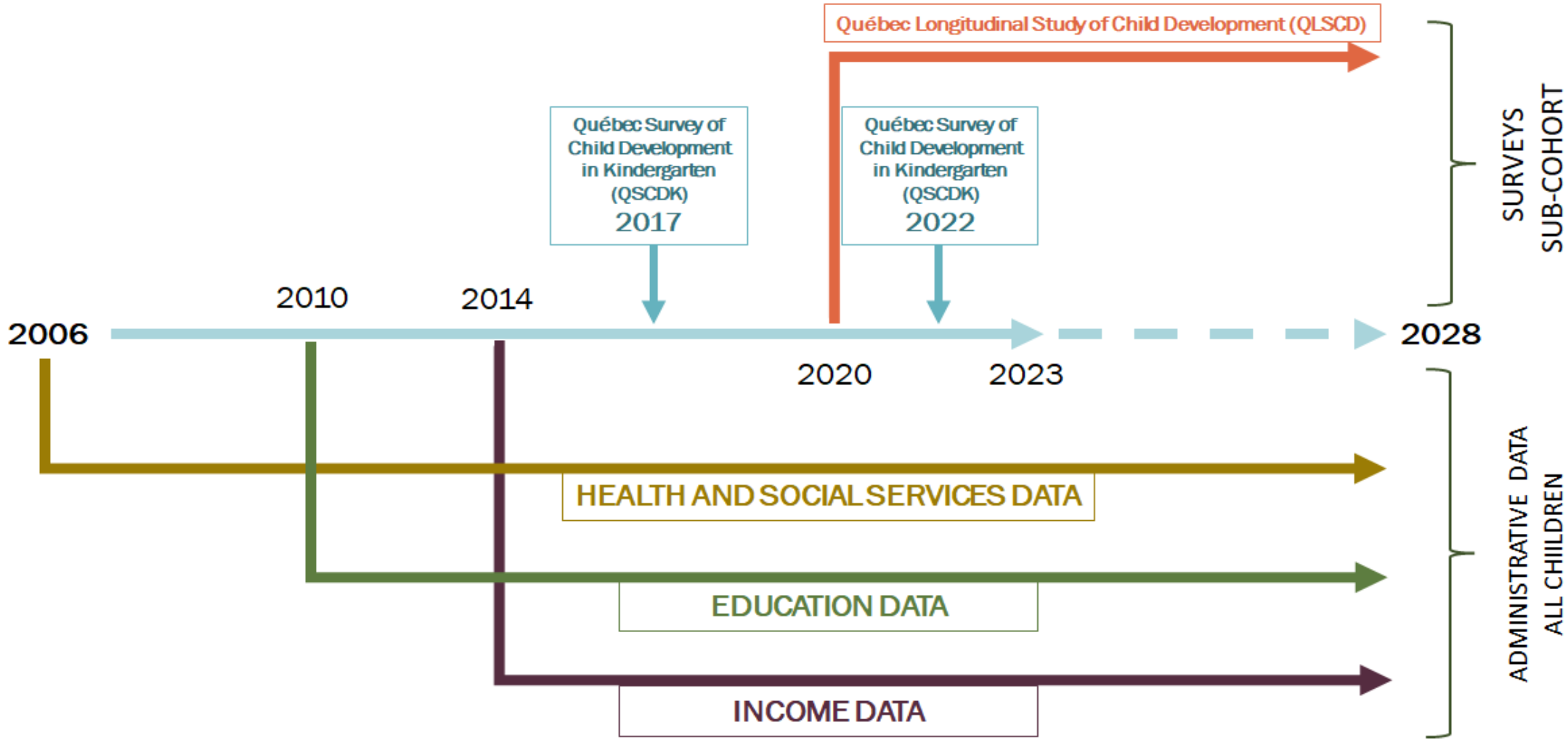


Dépenses publiques en éducation: Gouvernement du Québec (2025). Rapport sur le financement des services publics – 2023-2024.
Dépenses publiques en santé : Institut canadien d'information sur la santé (2024). Base de données sur les dépenses nationales de santé, Tableau E.1.25.1.
Développement du cerveau : Heckman (2003), Human capital policy

Why access to administrative data matters for research on health and education services

- Research based data collections have specific limitations
- Researchers expertise can be used

Figure 1: ‘Enfants du Québec’ dataset



Model:

- **Federally funded research linked to admin data**
- **Canadian Longitudinal Health Survey on Children and Youth (CHSCY 2023):**

What is needed

- Show usefulness
- One-time consent, risk-proportionate governance
- Common data linkage ID
- Federated secure-by-design environment

- **What does it mean for the national research landscape that the RAMQ don't share their data with CIHI? What is QC missing out on and what is the rest of Canada missing out on?**
-
- **What advances could be made in sharing data from the single-payer systems across the country? What are the easy wins, and valuable drawn-out campaigns?**
-
- **"What's your health data sharing/management wishlist? If you were a short-term dictator what would you rush to push through while you had the chance?"**

Neurogénèse est à son maximum au début de la vie

Center on the Developing Child
HARVARD UNIVERSITY

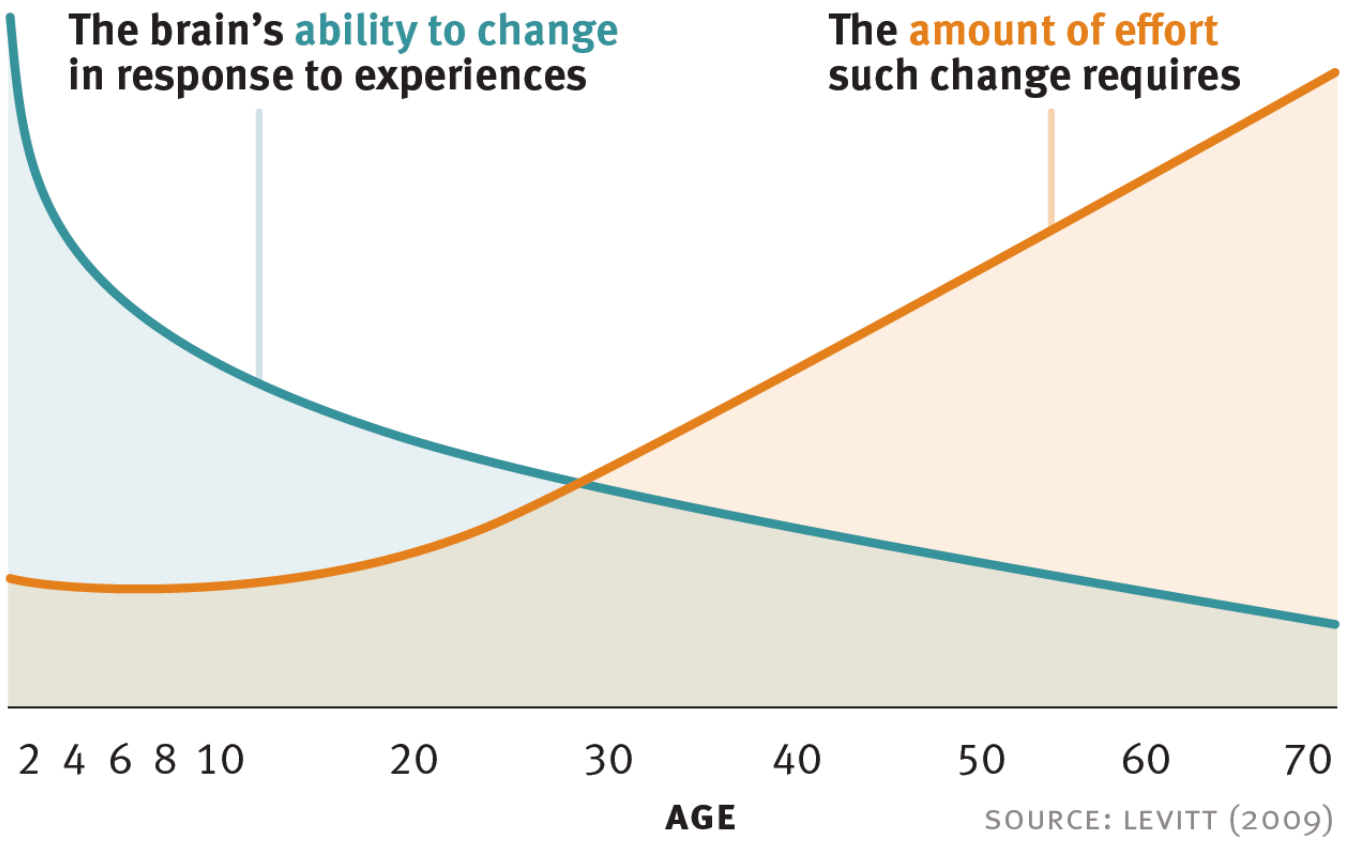
nature

Early fetal development of the human DG
S F Sorrells *et al. Nature* **555**, 377–381 (2018) doi:10.1038/nature25975

Does something need to fundamentally change about the way participants give consent to providing data for research? and, if so, what inroads are we going to have to make in communicating how health data are managed and shared to lay-audiences?

- Establish a clear public-interest basis and harmonize processes across provinces
- Make management and sharing understandable and co-designed:

Plasticité du cerveau: 0-70 ans



- Common linkage ID and national metadata standard
- Single pan-Canadian front door with harmonized rules and timelines One portal for applications and reviews (ethics, legal, security), using standard inter-jurisdictional agreements, transparent criteria, and SLAs (e.g., acknowledge ≤5 days, decision ≤90, data delivery ≤30 after approval).

"What's your health data sharing/management wishlist?

- One pan-Canadian gateway with binding SLAs, a common data model/linkage standard, and harmonized workflows across all provinces (including Quebec).
- Secure-by-default Trusted Research Environments Indigenous data sovereignty operationalized (OCAP/CARE), paired with radical transparency (public scorecards) and incentives tied to access quality and research impact.

Danish

1. Two complementary “research services,” both with secure remote access

- Statistics Denmark (DST) provides pseudonymized microdata across many domains (demographics, income, education) via its Research Services; analysts work on DST servers through remote desktops—no raw data leave the environment. dst.dk+1
- The Danish Health Data Authority (DHDA) provides national health registers via its Secure Research Platform, also remote-only. english.sundhedsdatastyrelsen.dk+1

2. Linkage across registers using the CPR number (under strict controls)
   A unique personal identifier (CPR) enables high-quality linkage between health, education, and social registries; researchers receive only de-identified/encoded IDs inside the secure environment. Taylor & Francis Online+1
3. Education data are comprehensive and longitudinal
   DST’s Student Register tracks educational trajectories from preschool through PhD and is updated annually; it’s widely used for population-level education research and for linkage to health and social outcomes. dst.dk+2dst.dk+2
4. Combining health and education in practice
   Projects can have DHDA deliver approved health extracts directly into a DST project workspace (secure transfer), allowing analysis with DST’s other registers (e.g., education, income) in one TRE. Approved software includes SAS, Stata, and R; only disclosure-controlled outputs can be exported. english.sundhedsdatastyrelsen.dk+1
5. Governance, eligibility, and access
   Access requires an approved project, a recognized institution, and data-protection approvals; foreign researchers typically work via Danish partners or specific arrangements set by DST/DHDA. The overall approach aligns with “safe settings/outputs” principles. dst.dk+1

- Why it works: a federated, secure-by-design setup with a common identifier for linkage, mature national registers, and remote analysis environments—yielding fast, comparable, population-scale research without moving raw data outside custodial platforms.

Does something need to fundamentally change about the way participants give consent to providing data for research? and, **if so, what inroads are we going to have to make in communicating how health data are managed and shared to lay-audiences?**

- Here are five concise points you can use on the panel.

1. Shift from one-time consent to ongoing, risk-proportionate governance
   Move beyond episodic consent toward a hybrid model: broad consent under clear governance, with dynamic/meta-consent so participants can set preferences by data type and use. Embed independent oversight (e.g., data trusts, citizen committees), auditable access logs, continuous opt-out, and proportional controls based on risk.

2. Clarify the public-interest basis and harmonize across jurisdictions
   Acknowledge that some minimal-risk, high-benefit uses can proceed under a well-defined public-interest basis with strict safeguards, even when individual re-contact is impractical. Align consent metadata, privacy impact assessments, and access procedures across provinces to reduce friction in multi-jurisdictional projects.

3. Make data management visible, traceable, and understandable
   Explain the full data lifecycle in plain language: collection, linkage/pseudonymization, where data are held, who can access, for what purpose, retention and destruction. Provide “consent receipts,” participant dashboards (what was shared, with whom, why), and clear recourse (withdrawal, complaints). Publish annual transparency reports and incident/audit summaries.

4. Co-design communication with affected communities
   Co-create forms, FAQs, and risk messages with patients, parents (for pediatric data), Indigenous partners (respecting OCAP/CARE), and under-represented groups. Use deliberative forums and usability testing to reduce information asymmetry and build legitimacy.

5. Communicate risks and benefits realistically—and measure understanding
   Standardize how we describe residual re-identification risk and the technical/organizational controls that mitigate it. Pair this with concrete public-health impacts from past data uses. Track public understanding (e.g., brief comprehension checks, surveys) and iterate materials accordingly.

- Bottom line: we shouldn’t discard consent—we should situate it within living, transparent, community-informed governance that is harmonized across Canada and proportionate to risk.