



MICYRN

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Canada Fast Facts



- 10 M sq km
- 34.5 M people
- 16% aged 0–14y
- 2/3 European descent





Canada Fast Facts



National policies

- Health
- Privacy
- Ethics
- Drug approval

interpreted by 10 provinces and 3 territories
and First Nations (federal)





Canada Fast Facts



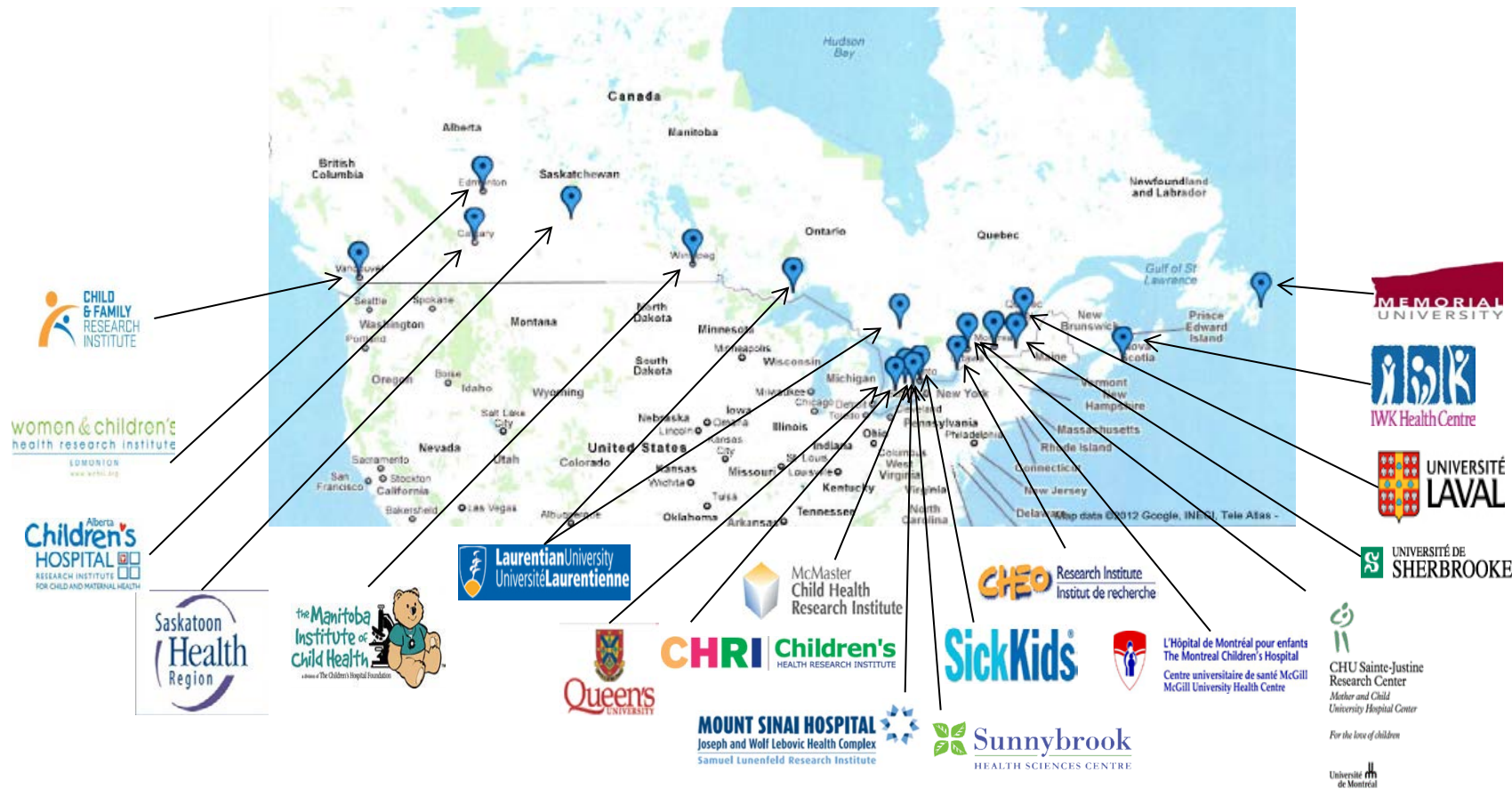
Provinces control:

- Standards of care
- Drug formulary
- Type of assessments
- Access to health and other data





Incorporates 20 Organizations



[illegible]



Strong Partnerships

CCYHC Coalition joins:



National Infant,
Child and Youth
Mental Health
Consortium

Networks capture:

- 70% high risk maternity beds
- all the pediatric tertiary beds
- all NICUs
- all PICU beds
- all specialty clinic practices
- all Ped academic ERs*



MICYRN Strategy at a Glance

Vision

“Better Health for Mothers and Children”

Mission

“Catalyzing advances in maternal and child healthcare
by connecting minds and removing barriers to high-quality health research”

Strategies

Forge collaborations in order to encourage exchange of ideas and innovations and achieve economies of scale.

Facilitate multijurisdictional research by addressing national and international barriers to collaboration in order to achieve efficiencies and optimize the investment in research.

Inform best practices in order to advance the quality and impact of research

Thematic Areas

Clinical Trials

DOHaD

Rare Diseases

Tactics

Engaging national and international stakeholders
Research Partnerships

Maximizing research outputs
Pregnancy/Birth Cohort Coalition:
Harmonized data and governance

Creating a coalition of Research Networks
Practice evaluation, learning and research networks

Ensuring safe and high quality studies of new and existing interventions
Clinical Trials Platform

Advancing quality & consistency of ethics review for multi-site studies
Research Ethics Platform

Improving data quality, reliability and reporting
Clinical Research Informatics Platform

Developing evidence-based best-practices
Standards and Guidance

Enabling patient input to the research process and outcome measurement
Young Persons Advisory

Supporting meaningful outcome quality management and timely uptake of results.
Research and Clinical Care Integration

Enablers

Learning & Accountability

Strategic Thinking

Administrative Coordination
Logistical Support



DATA

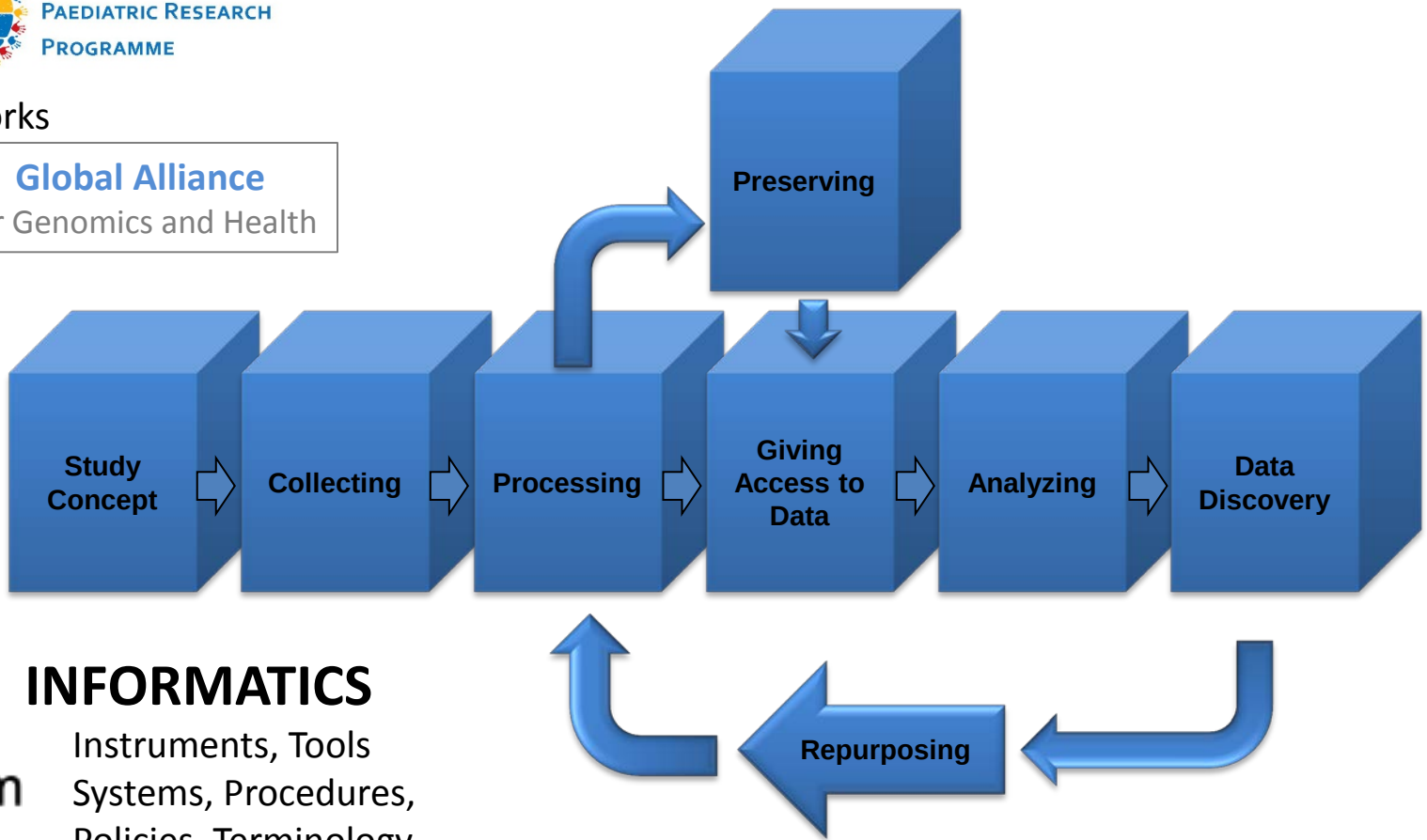
ELSI



P3G INTERNATIONAL
PAEDIATRIC RESEARCH
PROGRAMME

Issues
Guidance/Frameworks
Ethics Review
Consent

Global Alliance
for Genomics and Health



INFORMATICS

Instruments, Tools
Systems, Procedures,
Policies, Terminology



Figure adapted from: DDI Structural Reform Group. "DDI Version 3.0 Conceptual Model." *DDI Alliance*. 2004. <<http://www.icpsr.umich.edu/DDI/committee-info/Concept-Model-WD.pdf>>.



COMMENTS

1. Networking encourages networking (MICYRN & ICN)
2. Networks beget networks (?“divide & conquer”)
3. “Sitting between 2 chairs” (site or PI dilemma to join/stay in USA or EU network or form Canadian network)
4. Need to market the value of Networks (ICN)
5. Need to ensure physician/site credit for being involved in Networks