

The Nascent Pan-Canadian Real-world Health Data Network (PRHDN)

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if you have not done so already, please download the CAHSPR app, it will be used for voting in the second half of this panel session

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Learn more and/or join the PRHDN at www.prhdn.ca

What is the PRHDN?

- National and provincial organizations from across Canada have developed a proposal to create a new **Pan-Canadian Real-world Health Data Network (PRHDN)** that will allow policy/decision makers and researchers from across Canada to make **effective use of linkable data holdings and expertise** in multi-province analyses **without requiring that data leave provincial boundaries**
- **No new organization will be created** – the PRHDN will be a distributed network that connects **existing national and provincial organizations** to bring the **benefits of distributed data network** approaches to Canada
- Instead of “bricks and mortar” PRHDN infrastructure will take the form of **reusable tools and processes** that change the shape of the Canadian data learning curve so that **users of data spend less time searching for data, gaining access and assembling datasets** and more time pushing the frontiers of inquiry

Context – Distributed Data Networks

Other countries are investing in distributed health data infrastructure:

– Farr Institute (UK) - £34 million (~\$69 million CAD)

Four-centres across the UK implementing a coordinated approach to data safe havens, digital laboratories for larger scale research, increased access to well-described datasets, and a forum to address governance, public engagement, training etc.

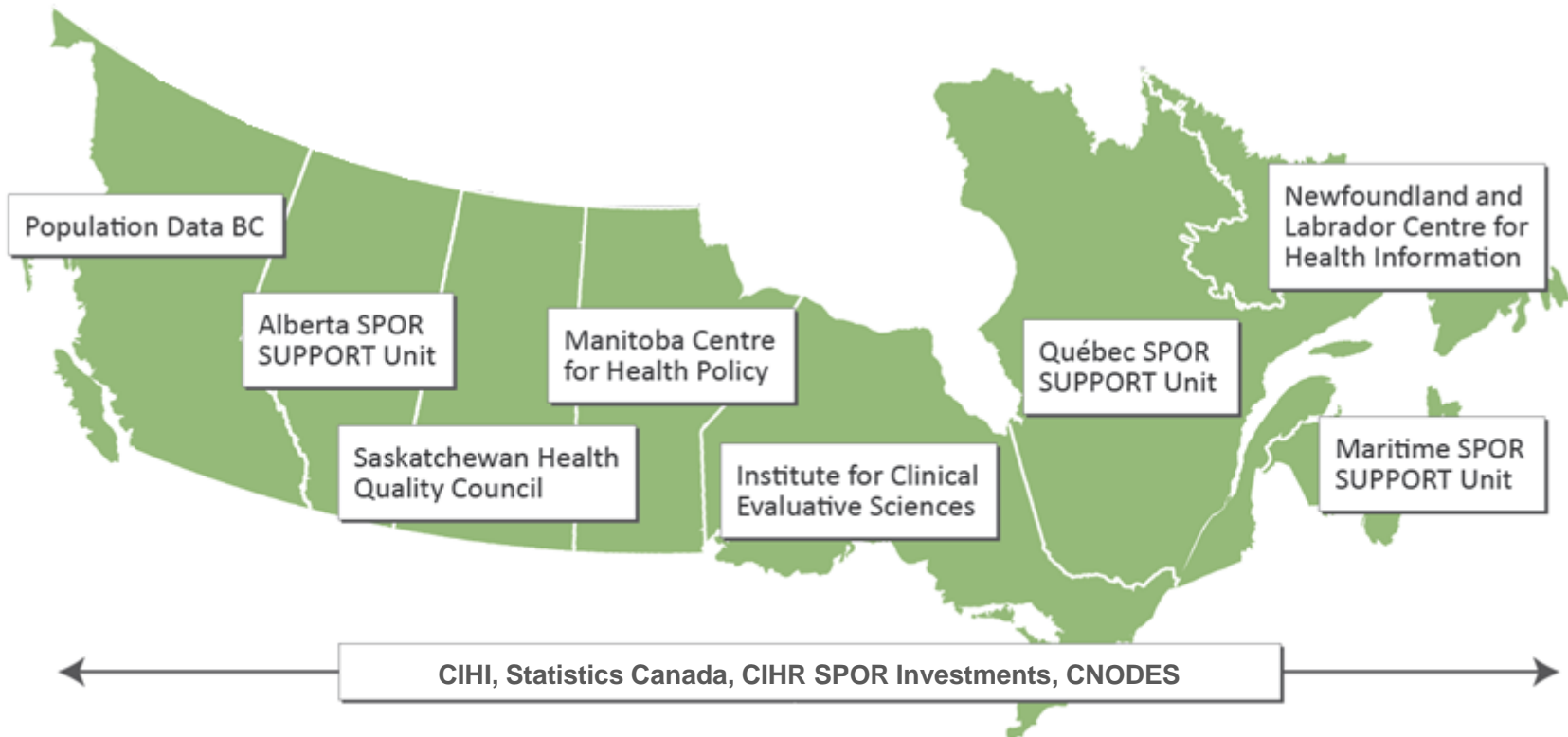
– Population Health Research Network/Australian Centre for Data Linkage – \$76 million AUD (~\$73 million CAD)

Six state/territory data linkage units and two National Linkage Units established to enhance Australia's ability to research, analyse and monitor health trends and health needs, e.g., large sample groups enable whole-of-population approach to health and health related research

– Sentinel Network (USA) –\$270 million USD (\$354 million CAD)

Nationwide system that uses electronic data to evaluate the safety of marketed drugs, devices, and biologics; each of Sentinel's 18 data partners is funded to create and maintain its own data formatted according to the common data model; centrally-developed code is sent to each partner site and run locally; summary results are generated by adding partner site results together

Canada's **small number of large single player health systems** combined with existing **national and provincial centres/networks** constitutes a **data advantage**



PRHDN: **Existing data assets and expertise** mean that the Canadian glass is already **almost full** when it comes to **world-class** multi-province **health data infrastructure**

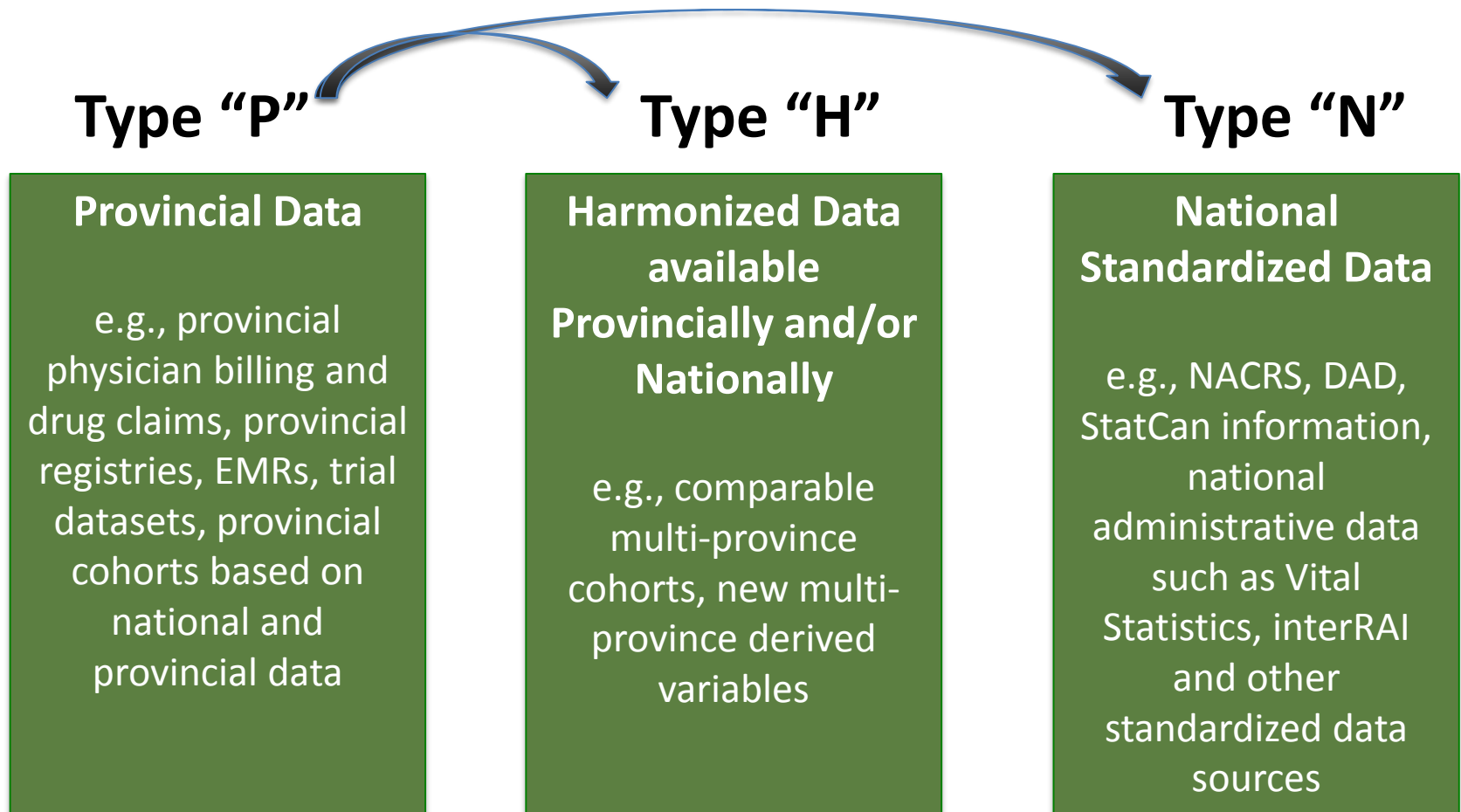


Closing this gap is a **collective** responsibility

Initial PRHDN planning focused on defining core data infrastructure that enables data from multiple PRHDN Organizations to be used in the same analyses

- Algorithms *that are applied to define cases for specific conditions within the data holdings from multiple provinces in a comparable way (e.g., an algorithm that defines cases of dementia in a comparable way in multiple provinces)*
- Harmonized common data *that are comparable between sites, either because they were standardized from the time of collection, or because data has been transformed into harmonized common data using algorithms*
- Common analytic protocols *that outline how to work with non-harmonized data (e.g., provincial data in unaltered form) and obtain results that can be pooled or combined even though the data are not comparable*

PRHDN: A **mechanism** to connect different **types of data**



Begin with meta data and aggregate data sharing between types, over time select priority type "P" data become type "H" and/or type "N"