# Understanding Health Data Social Licence

## An international comparison of community attitudes on the use of health data in Canada & Australia

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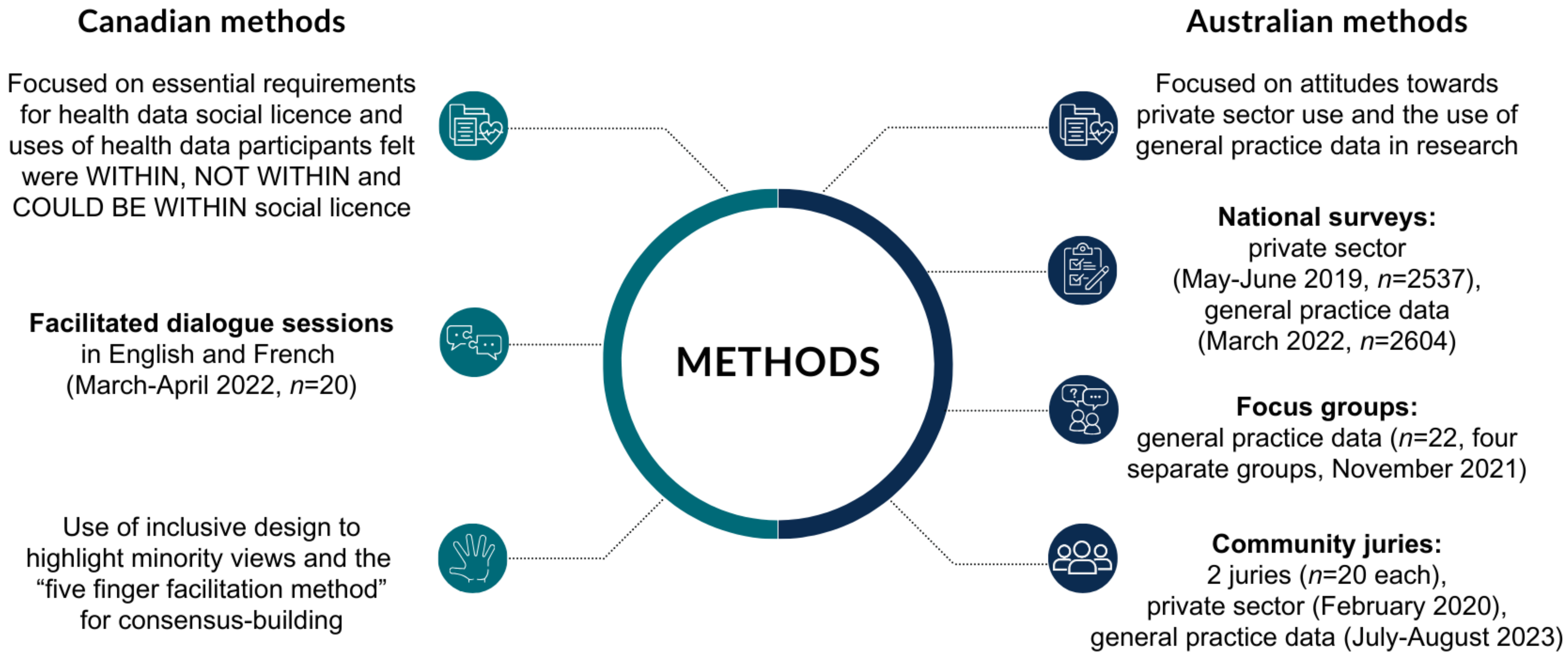
## BACKGROUND

Research has found general but *conditional* support for health data being used for public benefit. Conditional support includes considerations related to privacy and security (e.g., the use of de-identified data), commercial motives (e.g., profit) and equity and fairness (e.g., ensuring data use does not result in discrimination against certain groups). **Health data social licence** is used “to describe which health data-related activities have the support of members of the public, and under what conditions”.

Health Data Research Network Canada (HDRN Canada) and Population Health Research Network Australia (PHRN Australia) are collaborative network organizations dedicated to advancing multi-regional health research. Both organizations have conducted research to better understand community attitudes on the use of health data in research. The objectives of this work are to compare both organizations’ approaches to understanding community attitudes on health data use, and how social licence may differ, between Canadian and Australian populations.



**Canadian methods**

Focused on essential requirements for health data social licence and uses of health data participants felt were WITHIN, NOT WITHIN and COULD BE WITHIN social licence

**Facilitated dialogue sessions** in English and French (March-April 2022, $n=20$)

Use of inclusive design to highlight minority views and the “five finger facilitation method” for consensus-building

**Australian methods**

Focused on attitudes towards private sector use and the use of general practice data in research

**National surveys:** private sector (May-June 2019, $n=2537$), general practice data (March 2022, $n=2604$)

**Focus groups:** general practice data ($n=22$, four separate groups, November 2021)

**Community juries:** 2 juries ($n=20$ each), private sector (February 2020), general practice data (July-August 2023)

## RESULTS

Despite the different approaches taken, many conditions for social licence were **SIMILAR** across Canadian and Australian participants. Both groups agreed on conditions for health data social licence related to:

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|---|---|
| **Benefits** | Data sharing for public benefit is encouraged |
| **Equity & fairness** | Protection of and consultation with vulnerable communities |
| **Governance & oversight** | The importance of independent governance bodies |
| **Privacy & security** | Removal of identifying information and penalties for data breaches |
| **Transparency & data literacy** | Results of research made available in plain language |

However, there were some **DIFFERENT** views on uses of health data related to:

| | |
|---|---|
| **Personal control & consent** | Canada: opt-in consent preferred<br>Australia: opt-out consent or waiver of consent preferred |
| **Private sector involvement** | Canada: some mistrust in private sector; concerns of exploitation by commercial organizations<br>Australia: support for sharing data with private sector for research & development with conditions on sharing (e.g., penalties for misuse) |

## WHAT WE HEARD

### Benefits

*“To support optimized health system resource management… the discovery of new treatments”*

### Equity

*“…we’re worried that as a jury… we’re unable to make informed decisions for everybody in the community”*

### Governance

*“People need to trust the data is being collected properly, secured, and used appropriately”*

### Privacy

*“I think the only way you can trust people is if there are huge penalties for mistrust or misuse or selling the information…”*

### Transparency

*“The language should be a language everyone can understand – no ACRONYMS”*

### Consent

*“No sharing of data without the consent of the person in question”*

*“I think opt-out is obviously the best one … you will get the best data”*

### Private sector

*“The private sector cannot be trusted to be in the public’s best interest”*

*“Health data [should be] available to the private sector to ignite innovation for public benefit”*

## CONCLUSIONS

This comparative exercise contributes valuable insights into the ongoing dialogue surrounding community attitudes towards health data use.

Contextual factors that affected community support for health data use in research likely included the specific populations engaged, the type(s) of data being discussed, the timing of the engagement and the engagement approach use. Continued research monitoring health data social licence across populations is imperative for public trust while gaining full benefits from health data use in research.

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Réseau de recherche sur les données de santé du Canada
Health Data Research Network Canada

CIHR IRSC
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PHRN Population Health Research Network

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