CIHI's Equity Stratifiers: Modernizing our sex and gender data standards

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Outline

CIHI's approach to health equity

Measuring Health Inequalities: A Toolkit

Sex & Gender Standards

- **Implementation challenges**
- **Results of P/T engagement**
- **Next steps**

Some terms we use

Health equity is the absence of unjust, avoidable differences in health care access, quality of care or care outcomes

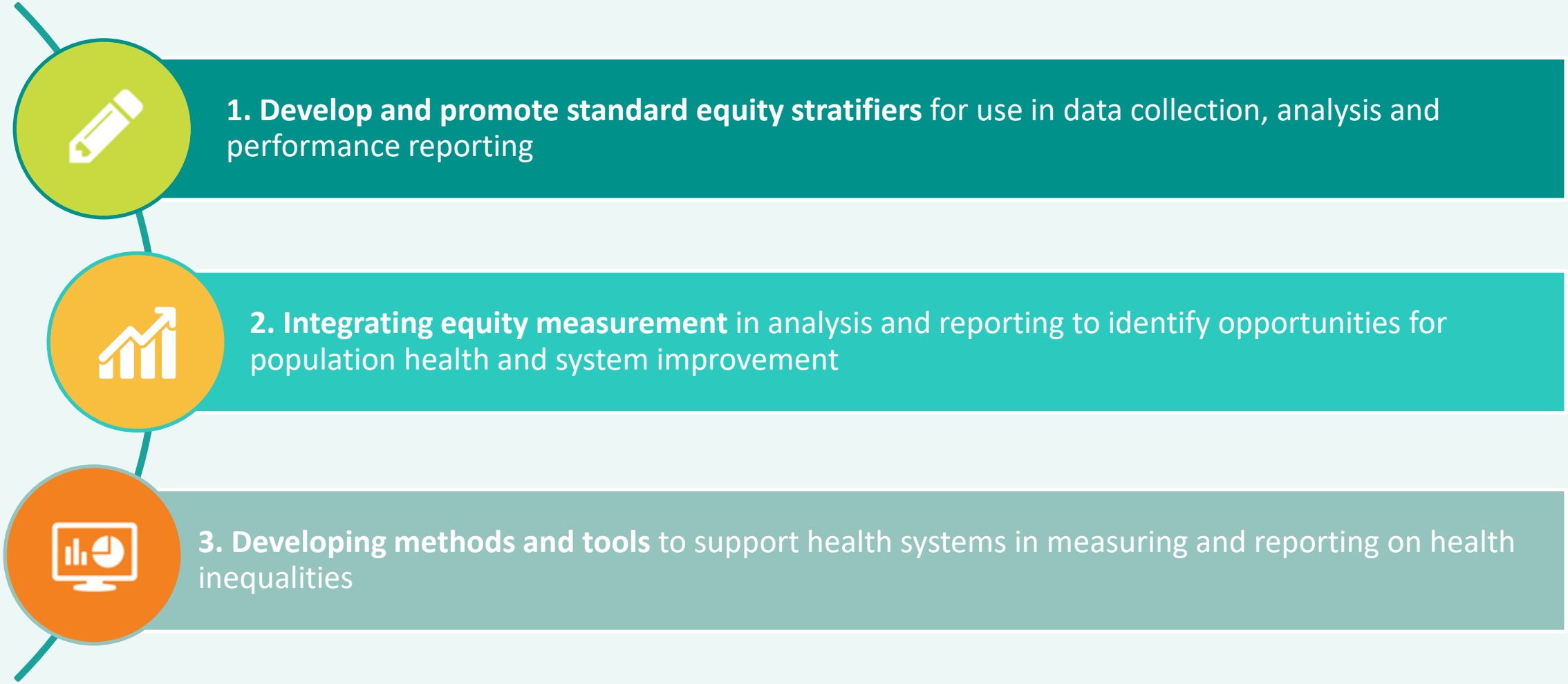
Health inequalities are measurable differences in health care which may or may not be fair

Equity stratifier is a demographic, social, economic, or geographic descriptor that can identify population subgroups for the purpose of measuring differences in health care

Equitable care does not differ by geography, income, sex, gender, race, and other characteristics that can be used to identify patient populations

Measuring inequalities across population subgroups allows us to prioritize differences in health care that can be acted on (improved) and used to measure progress toward health equity

CIHI's Approach to Health Equity



Why is Health Inequalities Measurement Important?

Unless specifically measured, inequalities in health and health care can go unnoticed by health systems even as they strive to improve care access, quality and outcomes

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You can’t improve if you don’t measure

- Equity is a universal goal of health systems, yet routine equity measurement is limited
- Tyranny of the Average -> Overall gains in population health and health system performance may mask persistent inequalities between populations

Performance measurement and quality improvement initiatives need a cohesive measurement plan that captures overall averages as well as the distribution across subpopulations

Measuring Health Inequalities: An Introduction - YouTube

Measuring Equity through Sociodemographic Variables

"It's data about a person"

Record Level Socio Demographic Variables can include:

- Sex & gender
- Race, Ethnicity
- Indigenous identity
- Sexual orientation
- Religious affiliation
- Socioeconomic status
- Education

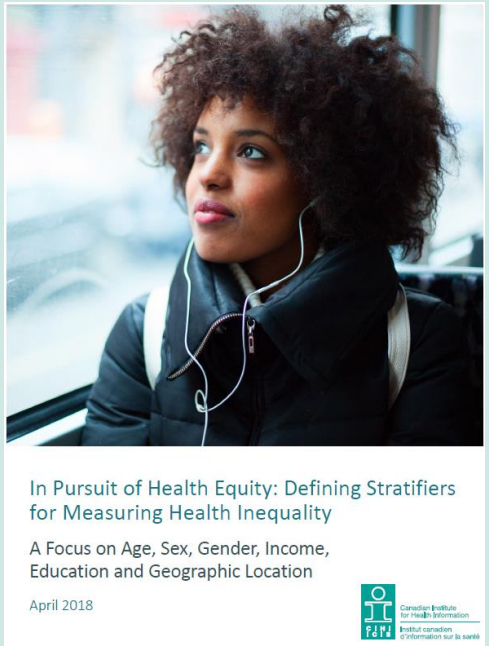
Area-Based Measures of Inequity can include:

- Race, Ethnicity
- Indigenous identity
- Socio economic status
- Education
- Urban vs. rural & remote

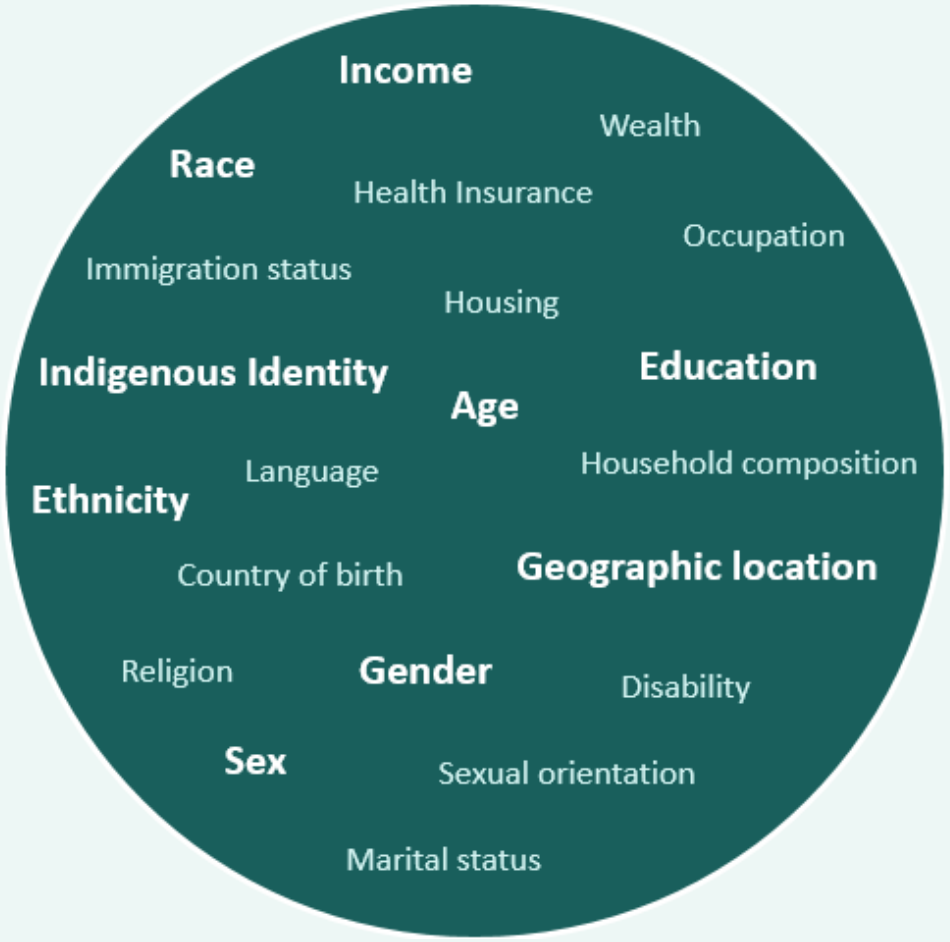
PROS AND CONS FOR BOTH

Prioritizing Data Needs for Assessing Health Equity

[Pan-Canadian Dialogue on health equity](#) **(2016)**



[Defining Stratifiers for Measuring Health Inequality](#) **(2018)**



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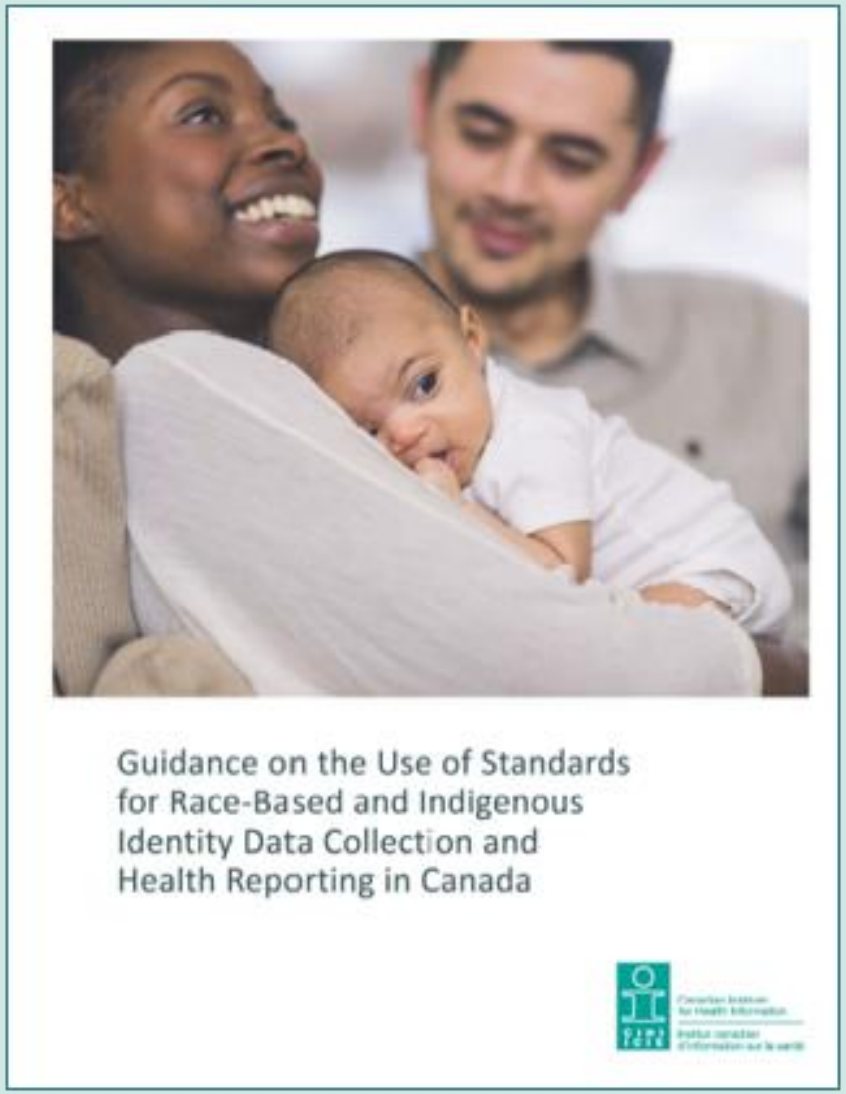

Guidance on Race-based and Indigenous Identity Data

- CIHI released guidance and standards on racialized group and Indigenous identity for voluntary adoption by health systems.
- These standards include 2 data collection items: a distinctions-based measure for Indigenous identity and a race-based data element.
- Community engagement, data governance agreements and processes for safe collection and use are essential for implementation.

Measuring Health Inequalities: A Toolkit

- Tailored to analysts and researchers with varying knowledge and skill sets
- Consists of guidelines and resources organized in 3 phases:

https://www.cihi.ca/en/measuring-health-inequalities-a-toolkit

Equity Stratifier Infosheets

Equity Stratification | June 2022

Racialized Group Stratifier: Guidance on Measuring and Reporting Inequalities

Definition

Construct: Self-identified racial group

Race is a social construct used to judge and categorize people based on perceived differences in physical appearance in ways that create and maintain power differentials within social hierarchies. There is no scientifically supported biological basis for discrete racial groups.[1, 2] However, interpersonal and structural racism and discrimination create inequities in health care access, quality, experiences and outcomes.

This reporting guideline is based on the minimum standard that the Canadian Institute for Health Information (CIHI) developed for the collection of race-based data. Note that the standard focuses solely on the concept of race, rather than race and ethnicity. For more information, see CIHI's page on race-based and Indigenous identity data. This document focuses on the use of the race-based data standard for reporting.

Reporting analyses disaggregated by race can help identify inequities and inform interventions to address them. Appropriate community engagement and data governance practices should be implemented to minimize the potential risks and harms, such as stigma or discrimination. Guidance for implementation is provided in *Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada*.

Measure: Racialized group

CIHI's racialized group stratifier was adapted from standards published in 2018 by the Ontario Anti-Racism Directorate for the identification and monitoring of systemic racism.[3]

For individuals who select more than one race category, additional categories for mixed racialized groups can be created (e.g., Black and White, Black and East Asian). How mixed-race groups are categorized will depend on the available data and reporting context.

https://www.cihi.ca/en/equity-stratifiers

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Spotlight on Equity: Modernizing CIHI's sex and gender data standards

Current state of CIHI's sex and gender data standards

- **CIHI's current sex and gender data standards reflect a 2-step approach of using both Sex at Birth and Gender information where available.**
  - Aligns with Statistics Canada's standards used in the 2021 Census of Population.
  - Cross-tabulating Sex at Birth and Gender information allows transgender individuals to be identified and represented in CIHI's data.
- **We have heard that the 2-step approach might not be appropriate or relevant where the information will be used for both *clinical care* and *health system use.***
  - There might be a better way to identify the transgender population and report on the inequities they face in health care.

CIHI's Sex at Birth Standard

A code that identifies the category assigned to an individual and recorded at a person's birth (e.g., recorded on original birth certificate). Sex is a complex biological concept that includes anatomy, physiology, genes and hormones. Assignment of sex at birth is typically based on external anatomy and limited to female and male. Sex at birth may also be assigned as intersex, which is a term used to describe a range of sex characteristics. Not all intersex variations are visible or detected at birth, but when they are, sex at birth may be recorded as "intersex" or assig

Name	Value code	Value label	Value meaning
Sex at Birth	F	Female	n/a
	M	Male	n/a
	I	Intersex	Intersex is a term used to describe a range of sex characteristics. Some intersex variations are visible or detected at birth. When they are, an individual's sex at birth may be recorded as "intersex" or may be recorded as "female" or "male".
	UNK	Unknown	Includes not stated, not recorded, a value is applicable but not known.

Source: CRDM Toolkit

CIHI's Gender Standard

Gender is a social construct that encompasses gender identity and lived gender (i.e., gender expression) as a man, woman, both, neither or anywhere along the gender spectrum.

Name	Value code	Value label	Value meaning
Gender	F	Female	n/a
	M	Male	n/a
	X	Another gender	Includes persons who reported their gender as being other than male or female. It includes persons who reported being unsure of their gender, being both male and female, or neither male nor female. Ideally, this is collected as open text field "Please specify: (open text)."
	UNK	Unknown	Includes not stated, not recorded, a value is applicable but not known.
	NA	Not Applicable	Includes if question is not appropriate to ask (e.g., inappropriate to ask children).

Source: CRDM Toolkit

Challenges to implementation

- **CIHI receives a large amount of administrative data which often comes from a health card swipe during patient registration.**
  - In April 2022, the *Gender* data element in CIHI's Discharge Abstract Database (DAD) was re-labelled *Recorded Sex or Gender* to more accurately reflect the data (which is currently a conflation of sex and gender sourced from health card).
- **Open text response options are not practical nor feasible in most health care databases.**
- **When data holdings are updated, there are several downstream impacts that must be considered, including the impact on established indicators and methodologies.**

What we've heard

HL7 Gender Harmony Project and Canada Health Infoway's Sex and Gender Working Group (SGWG)

- Concerns with collecting sex at birth in a clinical setting, particularly when this information is not relevant to the care being provided.
- Some transgender and non-binary individuals feel harmed or unsafe being asked questions about their sex at birth and/or sex for clinical use.

CIHI's Canadian Patient Experience Survey – Inpatient Care (CPES-IC)

- Includes both a sex at birth and a gender question with an explanatory preamble.
- Questions are asked directly and not supplied from administrative data.
- Questions tested favourably during cognitive testing – patients felt that the preamble was "clear and that it may influence others to answer".

No "one size fits all" standard

- **We may need to implement sex and gender standards differently in different contexts:**
  - A two-step approach for collecting sex and gender data may work in the context of surveys (e.g., patient engagement surveys), where a preamble can be provided.
  - A different implementation of the standard may be needed in the clinical portion of an EMR or HIS, in the administrative/registration portion of an EMR or HIS, etc.
  - A different data standard may be needed for implementation in systems that collect data about providers or health workforce resources.
- **We have many willing external partners who can help us resolve this topic by bringing different expertise to the table.**

Results of provincial/territorial and vendor engagement

Provincial/territorial and vendor engagement

- **With the support of an external consultant, CIHI engaged with the provinces and territories, as well as major EMR and HIS software vendors, to better understand the sex and gender data that is currently being collected within the jurisdictions, including the flow of information between systems.**
  - Update to an environmental scan that Canada Health Infoway had completed in 2019.
- **Conducted 12 one-hour interviews with provincial and territorial stakeholders to gather input on the current state, challenges and opportunities for the collection and use of sex and gender data standards in their jurisdictions.**
- **Structured questionnaires and surveys were developed to help guide the engagement.**

What sex and gender data is being collected?

Category	Values	YK	NWT	NU	BC	AB	SK	MB	ON	QC	NB	NS	NF	PE	EPIC	CERNER	MEDITECH	TELUS	INTRA-HEALTH
SEX At Birth, Legal Sex, Administrative Gender	Male	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
	Female	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
	Unknown	X	X	X	X	X	X	X	X		X	X	X	X	X	X	X	X	X
	Undifferentiated			X	X			X	X		X					X	X		
	X (mostly for MSP)	X	X			X		X		X		X			X				X
	Not Recorded on Birth Certificate					X									X				
	Other	X		X	X				X				X				X	X	
	Non-Binary			X													X		X
GENDER Gender Identity, Preferred Gender	Female				X	X		X	X				X		X	X		X	X
	Male				X	X		X	X				X		X	X		X	X
	Transgender							X										X	
	Transgender M to F				X	X			X				X		X	X			
	Transgender F to M				X	X			X				X		X	X			
	Intersex				X	X			X				X		X	X		X	X
	Questioning					X			X						X				
	Prefer Not to Answer					X			X				X		X			X	
	Two-Spirit				X	X			X				X		X	X		X	X
	Non-Binary				X	X									X	X			X
	Cis				X											X			
	Gender Creative				X											X			
	Agender				X											X			

Key findings from P/T engagement

- **Overall lack of standardization of sex and gender data capture and use both *within* and *across* provinces and territories.**
- **Definitions for sex and gender information varied greatly as did the collection processes and use for administrative, clinical and analytical purposes.**
- **Some provinces captured structured gender data, but generally only in one system (e.g., HIS, EMR) or jurisdiction.**
- **Processes for collection of Sex at Birth / Legal Sex were similar across most of the P/Ts for vital statistics recording and registration processes for health care insurance cards.**
  - However, the use of these values in downstream workflows (e.g., hospital or clinic registration, physician billing) varied greatly across P/Ts.

Common challenges

- **System limitations.**
- **Lack of standardization of concepts, names, definitions, values available across systems.**
- **No source of truth.**
- **Lack of lived experience input into the requirements for sex and gender information capture.**
- **Clinicians and front-line staff lack the training and education on how to ask potentially sensitive questions.**
- **Patient/client lack of trust in government agencies and the potential use of sensitive information.**

Participant from Newfoundland and Labrador

Key findings from vendor engagement

- **All vendor solutions capture some form of Sex (at Birth, Legal Sex, Administrative Gender) for administrative purposes.**
  - Male, Female and Unknown were common values. Other values varied across solutions.
- **All vendor solutions (except for one), enabled the capture of structured, coded values for Gender (Gender Identity, Preferred Gender). However, the only common values were Male, Female, Intersex and Two-Spirit. All other values varied across solution.**
- **Vendors expressed that they would be open to adopting a national standard within their databases but cautioned that local customer requirements may supersede this.**

Next steps

Next steps

- **Continued engagement with the HL7 Gender Harmony project, ISO and Canada Health Infoway's Sex and Gender Working Group.**
- **Additional engagement:**
  - Individuals with lived experience
  - Indigenous partners
  - Clinicians and researchers
- **Continue working with partners to determine the best way to identify transgender individuals in our data so that their experiences can be accurately represented.**

Next steps

- **Initiate the process to update CIHI's sex and gender data standards to include Recorded Sex or Gender (data sourced from health card)**
  - Aligns with HL7 Gender Harmony standards in V2, CDA, and FHIR (R5)
- **Work towards standardizing Gender Identity values**
- **Continue working with Canada Health Infoway and Statistics Canada to determine what the eventual governance of these standards will look like**
- **Progress is better than perfection!**


Questions?

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