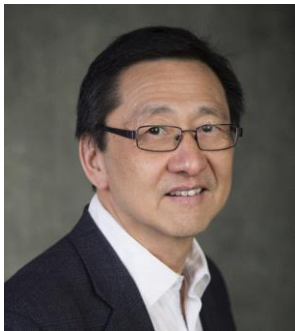# HEALTH INFORMATION SCIENCE SEMINAR SERIES

MODERNIZING
GENDER, SEX AND SEXUAL ORIENTATION
INFORMATION PRACTICES IN
CANADIAN ELECTRONIC HEALTH RECORD SYSTEMS

(GSSO in EHR)

March 10, 2021

Francis Lau PhD, Professor
On behalf of CIHR Planning Project Team, Infoway Sex-Gender Working Group,
and Contributing Members from Organizations and Communities
Email: fylau@uvic.ca

University
of Victoria

CIHR
IRSC | Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

This project has been funded through the CIHR Institute of Gender and Health

… acknowledge with respect the Lekwungen-speaking peoples on whose traditional territories the University of Victoria stands; the Songhees, Esquimalt and the W_SÁNEC ("w'Saanich") peoples, whose historical relationship with the land continues to this day.

… each of you will join me and acknowledge the privilege we have of coming together in the spirit of respectful dialogue from the traditional territories of indigenous peoples from across this land known as Canada

Agenda

1. What are the issues?
2. What did we do about it?
3. What did we find?
4. What's in the action plan?
5. What's next?

1. What are the issues?

➢ *"I go by Jane … but my chart still has my previous name John on it, even when I have told the clinic to update it. Then they called out John at the desk, and looked at me funny when I answered, everyone was staring … it was awful …"*

➢ A lesbian patient went to her women's wellness exam, and was handed an After Visit Summary with patient instructions on avoiding sexually transmitted diseases for heterosexual patients. All she could think of was *"… nothing on this page relates to me …"*

➢ Rodrigo is a 40-year-old trans man who went to the clinic with pelvic pain and spotting. A biopsy determined that he had cervical cancer *"… No one told me that I still need routine cervical Pap tests …"*

University of Victoria

CIHR IRSC | Canadian Institutes of Health Research | Instituts de recherche en santé du Canada

THE HEALTH OF LGBTQIA2 COMMUNITIES IN CANADA

Report of the Standing Committee on Health

Bill Casey, Chair

JUNE 2019
42nd PARLIAMENT, 1st SESSION

"… *LGBTQIA2 communities in Canada experience numerous health inequities … data collection [should] be improved in order to obtain a more complete picture of the health of gender and sexual minorities in Canada.*" [p2]

5

2. What did we do about it?

- *CIHR planning project* to create a coalition of organizations and communities to develop an action plan to improve the definition, collection and use of GSSO data in EHR systems for sexual and gender minorities (SGM)

- *Rapid reviews* – examined peer-reviewed and grey literature for current landscape, emerging issues and best practices

- *Environmental scan* – examined 52 databases and 55 data standards from 12 Canadian entities and 10 standards communities

- *Mind mapping & use cases* – modeled GSSO concepts and relationships with glossary of terms, and proposed use case scenarios and workflows

- *Group discussions* – held 8 presentations by leading practices, and 8 virtual sessions with 50+ participants from communities and organizations

University of Victoria

CIHR IRSC | Canadian Institutes of Health Research | Instituts de recherche en santé du Canada

3. What did we find?

➢ *Conflated single sex/gender data field with only male and female options*
  - Inconsistency in data field names and value options
  - Limited value options making SGM invisible
  - Expanded definitions challenging to implement in existing EHR systems

➢ *Key themes identified on issues and needs …*
  - Inclusive, culturally competent environment with precise GSSO terminology, standardized data collection policies
  - Guidelines for identifying and matching SGM patients with unique care needs
  - Use of anatomical inventories to remove sex and gender assumptions for ALL patients
  - Standardized GSSO data to guide care, support secondary use, expand evidence base on SGM health
  - Techno-socio-organizational aspects when implementing GSSO in EHRs

4. What's in the action plan? -link

1. Envisage an equity- and SGM-oriented health system vision and goal

2. Engage and partner with organizations and communities to modernize GSSO information practices to meet SGM needs

3. Establish GSSO terminology for patient care, health system use and research

4. Enable EHRs to collect, use, exchange and reuse standardized GSSO data

5. Integrate and tailor GSSO data collection with organizational structures, policies, use cases and workflow processes

6. Educate & train staff to provide culturally competent and safe care, and educate patients to understand need

7. Establish a central hub to coordinate this action plan over time and continue national conversation as next step

This plan focuses on **what** actions are needed, with details on **who, how** and **when** to be discussed and established later

University of Victoria

CIHR IRSC | Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

This project has been funded through the CIHR Institute of Gender and Health

8

4. What's in the action plan? … *Priorities*

1. Envisage an equity- and SGM-oriented health system vision and goal
2. Engage and partner with organizations and communities to modernize GSSO information practices to meet SGM needs
3. Establish GSSO terminology for patient care, health system use and research
4. Enable EHRs to collect, use, exchange and reuse standardized GSSO data
5. Integrate and tailor GSSO data collection with organizational structures, policies, use cases and workflow processes
6. Educate & train staff to provide culturally competent and safe care, and educate patients to understand need
7. Establish a central hub to coordinate this action plan over time and continue national conversation as next step
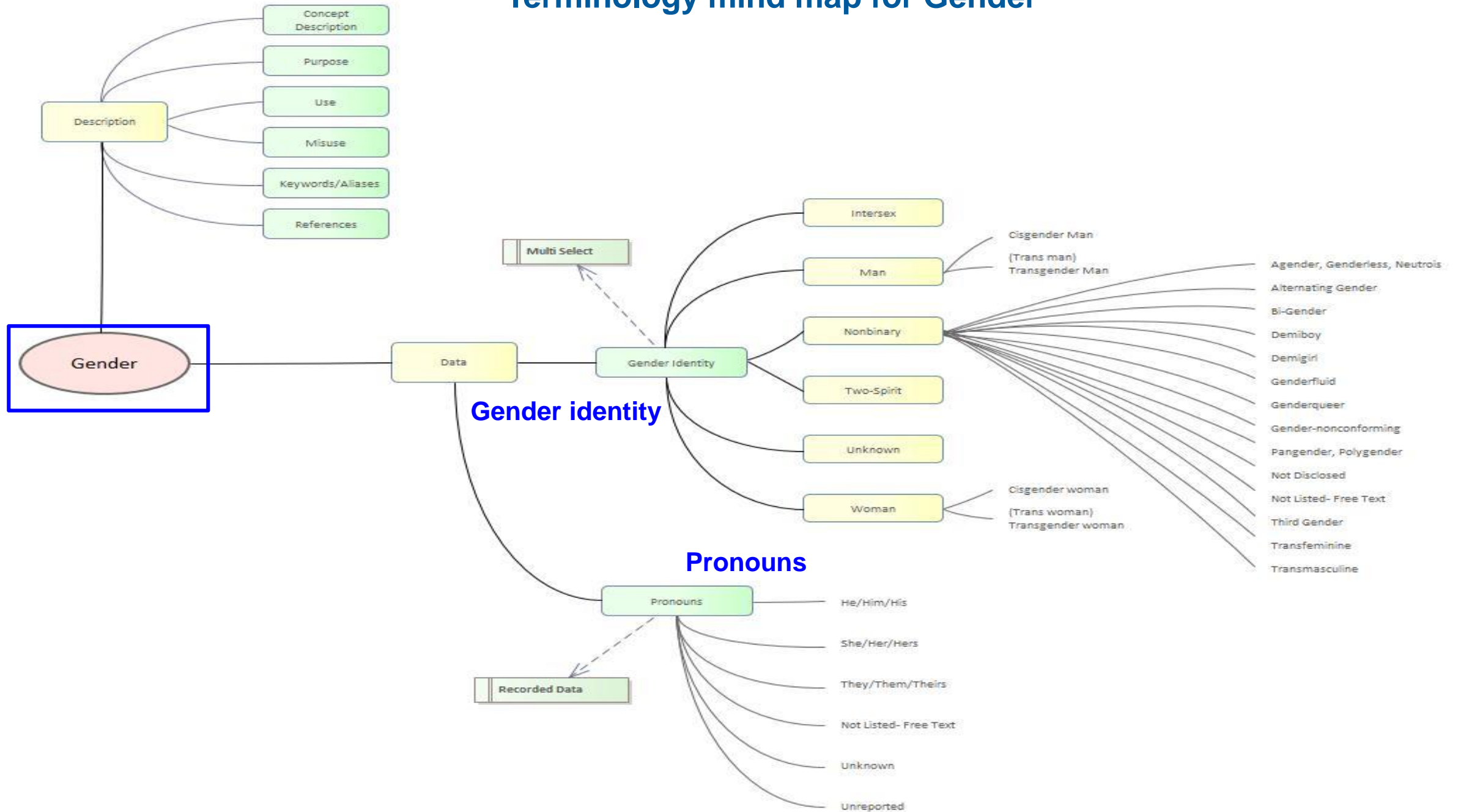
Priorities   1 Vision/Goal   2-4 Foundational   5-6 Strategic   7 Immediate

Scope coverage, Implementation options, Migration stages, Readiness/Needs Assessment

University of Victoria

CIHR IRSC | Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

This project has been funded through the CIHR Institute of Gender and Health
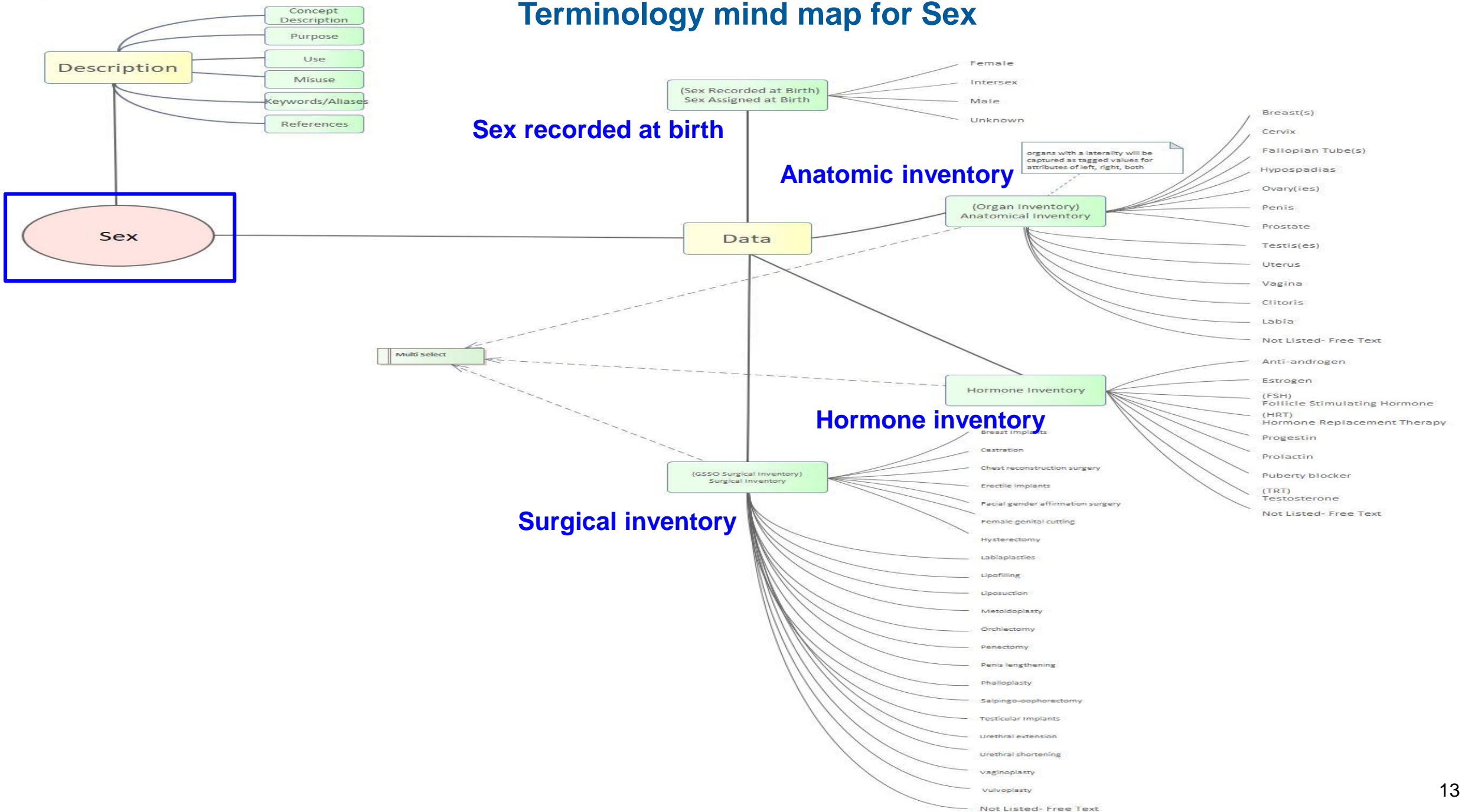
9

4. What's in the action plan? … *Action 3*

1. Envisage an equity- and SGM-oriented health system vision and goal
2. Engage and partner with organizations and communities to modernize GSSO information practices to meet SGM needs
3. Establish GSSO terminology for patient care, health system use and research
4. Enable EHRs to collect, use, exchange and reuse standardized GSSO data
5. Integrate and tailor GSSO data collection with organizational structures, policies, use cases and workflow processes
6. Educate & train staff to provide culturally competent and safe care, and educate patients to understand need
7. Establish a central hub to coordinate this action plan over time and continue national conversation as next step

4. What's in the action plan? … *Action 3*

1. Envisage an equity- and SGM-oriented health system vision and goal
2. Engage and partner with organizations and communities to modernize GSSO information practices to meet SGM needs
3. Establish GSSO terminology for patient care, health system use and research
   - ➤ Terminology mind maps and glossary of terms
   - ➤ Data elements and value sets
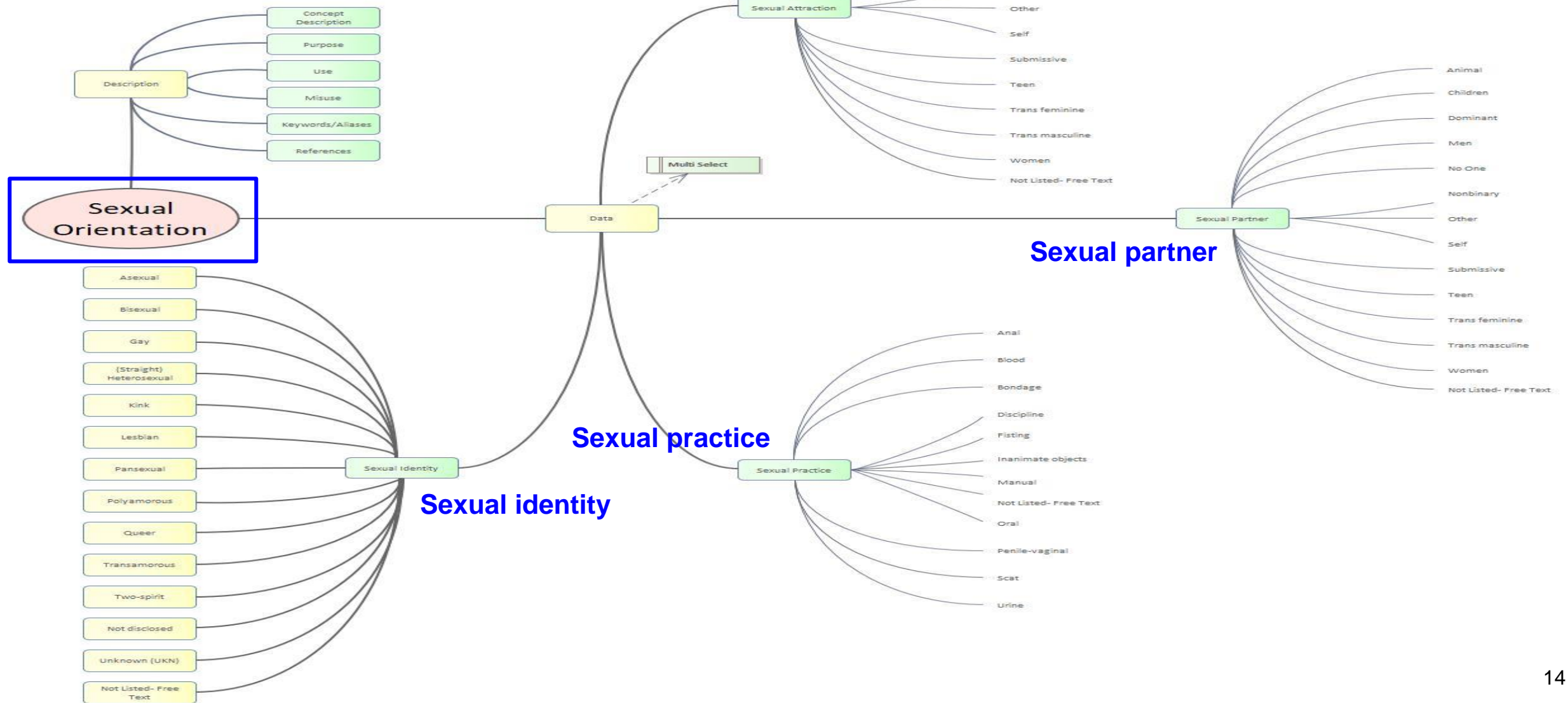   - ➤ Use case scenarios and workflows

Terminology mind map for Gender

12

Terminology mind map for Sex

Description
- Concept Description
- Purpose
- Use
- Misuse
- Keywords/Aliases
- References

Sex

Sex recorded at birth

Data

(Sex Recorded at Birth) Sex Assigned at Birth
- Female
- Intersex
- Male
- Unknown

Anatomic inventory

organs with a laterality will be captured as tagged values for attributes of left, right, both

(Organ Inventory) Anatomical Inventory
- Breast(s)
- Cervix
- Fallopian Tube(s)
- Hypospadias
- Ovary(ies)
- Penis
- Prostate
- Testis(es)
- Uterus
- Vagina
- Clitoris
- Labia
- Not Listed- Free Text

Multi Select

Hormone inventory

Hormone Inventory
- Anti-androgen
- Estrogen
- (FSH) Follicle Stimulating Hormone
- (HRT) Hormone Replacement Therapy
- Progestin
- Prolactin
- Puberty blocker
- (TRT) Testosterone
- Not Listed- Free Text

(GSSO Surgical Inventory) Surgical Inventory

Surgical inventory

- Breast Implants
- Castration
- Chest reconstruction surgery
- Erectile implants
- Facial gender affirmation surgery
- Female genital cutting
- Hysterectomy
- Labiaplasties
- Lipofilling
- Liposuction
- Metoidoplasty
- Orchiectomy
- Penectomy
- Penis lengthening
- Phalloplasty
- Salpingo-oophorectomy
- Testicular Implants
- Urethral extension
- Urethral shortening
- Vaginoplasty
- Vulvoplasty
- Not Listed- Free Text

13

Terminology mind map for Sexual Orientation

Sexual attraction

Sexual partner

Sexual practice

Sexual identity

14

Glossary of terms – As of Oct 6, 2020

Term	Definition
Gender	Refers to the gender that a person internally feels (gender identity) and/or the gender a person expresses (gender expression) in their daily life, including at work, while shopping or accessing other services, in their housing environment, or in the broader community. A person's current gender may differ from what is typically expected based on the sex a person was assigned at birth and may differ from what is indicated on their current legal documents. A person's gender may change over time Source – Goldman et al.
Legal Gender	Gender recorded on primary official government documents such as birth certificates and passports
Administrative Gender	Gender recorded on primary official government documents such as birth certificates and passports or on other documents such as health care cards or drivers licenses A term used in most existing electronic health record systems that refers to either one's sex or gender recorded and used for administrative purposes such as billing purposes. Also known as legal gender in some systems. Source - Burgess
Male Gender	This category includes persons whose current gender was reported as male. This includes cisgender and transgender persons who were reported as being male StatCan -link
Female Gender	This category includes persons whose current gender was reported as female. This includes cisgender and transgender persons who were reported as being female StatCan -link
Gender Diverse	This category includes persons whose current gender was not reported exclusively as male or female. It includes persons who were reported as being unsure of their gender, persons who were reported as both male and female, or neither male nor female StatCan -link
Gender Expression	Refers to the gender a person publicly expresses in their daily life, including at work, while shopping or accessing other services, in their housing environment or in the broader community StatCan -link How a person enacts gender in their everyday life. May include name, grooming, clothing, comportment. There are many reasons why a person may not feel that it is safe to express their gender identity in certain circumstances. Thus, a person's gender expression may or may not be a good representation of their gender identity. Source - Goldman et al.

15

Data elements and value options

Gender identity	
Pronouns	
Sex assigned at birth	
Anatomic inventory	
Hormone inventory	
Surgical inventory	
Sexual orientation	

Data elements and value options

Gender identity	Intersex, Man, Nonbinary, Two-Spirit, Unknown, Woman
Pronouns	He/Him/His, She/Her/Hers, They/Them/Theirs, *Not listed-Free text*, Unknown, Unreported
Sex assigned at birth	Female, Intersex, Male, Unknown
Anatomic inventory*	Breast(s), Cervix, Fallopian tube(s), Ovary(ies), Penis, Prostate, Testis(es), Uterus, Vagina, Clitoris, Labia, *Not listed-Free text*
Hormone inventory	Anti-androgen, Estrogen, Follicle stimulating hormone (FSH), Hormone replacement therapy (HRT), Progestin, Prolactin, Puberty blocker, Testosterone (TRT), *Not listed-Free text*
Surgical inventory	Labiaplasties, Lipofilling, Liposuction, Metoidoplasty, *Not listed-Free text,* Orchiectomy, Penectomy, Penis lengthening, Phalloplasty, Salpingo-oophorectomy, Testicular implants, Urethral extension, Urethral shortening, Vaginoplasty, Vulvoplasty,
Sexual orientation	Sexual identity, Sexual attraction, Sexual partner, Sexual practice

Data elements and value options

Gender identity	Intersex, Man, Nonbinary, Two-Spirit, Unknown, Woman
Man	Cisgender man, Transgender man/Trans man
Nonbinary	Agender/Genderless/Neutrois, Alternating gender, Bigender, Demiboy, Demigirl, Genderfluid, Genderqueer, Gender-nonconforming, Pangender/Polygender, Not disclosed, *Not listed-Free text*, Third gender, Transfeminine, Transmasculine
Woman	Cisgender woman, Transgender woman/Trans woman
Pronouns	He/Him/His, She/Her/Hers, They/Them/Theirs, *Not listed-Free text*, Unknown, Unreported
Sex assigned at birth	Female, Intersex, Male, Unknown
Anatomic inventory*	Breast(s), Cervix, Fallopian tube(s), Ovary(ies), Penis, Prostate, Testis(es), Uterus, Vagina, Clitoris, Labia, *Not listed-Free text*
Hormone inventory	Anti-androgen, Estrogen, Follicle stimulating hormone (FSH), Hormone replacement therapy (HRT), Progestin, Prolactin, Puberty blocker, Testosterone (TRT), *Not listed-Free text*
Surgical inventory	Labiaplasties, Lipofilling, Liposuction, Metoidoplasty, *Not listed-Free text,* Orchiectomy, Penectomy, Penis lengthening, Phalloplasty, Salpingo-oophorectomy, Testicular implants, Urethral extension, Urethral shortening, Vaginoplasty, Vulvoplasty,
Sexual orientation	Sexual identity, Sexual attraction, Sexual partner, Sexual practice

Use case scenarios and workflows

When should these data fields be accessed												
Circumstances, Data Fields and Value Sets	Registration	Scheduling	Insurance	Billing	Report/letter	Lab	Imaging	Prescribing	Sexual history	Gender-affirming care	Others?	Questions
Patient identification number												Examples
Chosen and legal name												
Birthdate												What data do we need?
Administrative/legal gender												How to identify patients?
Effective date												How to address patients?
Effective until date												How to communicate?
Pronouns												How to provide care?
Gender identity												How to protect privacy?
Sex recorded at birth												
Organ inventory												
Sexual orientation												

Use case scenarios and workflows

Figure 5. Sample Process of Collecting SOGI Data
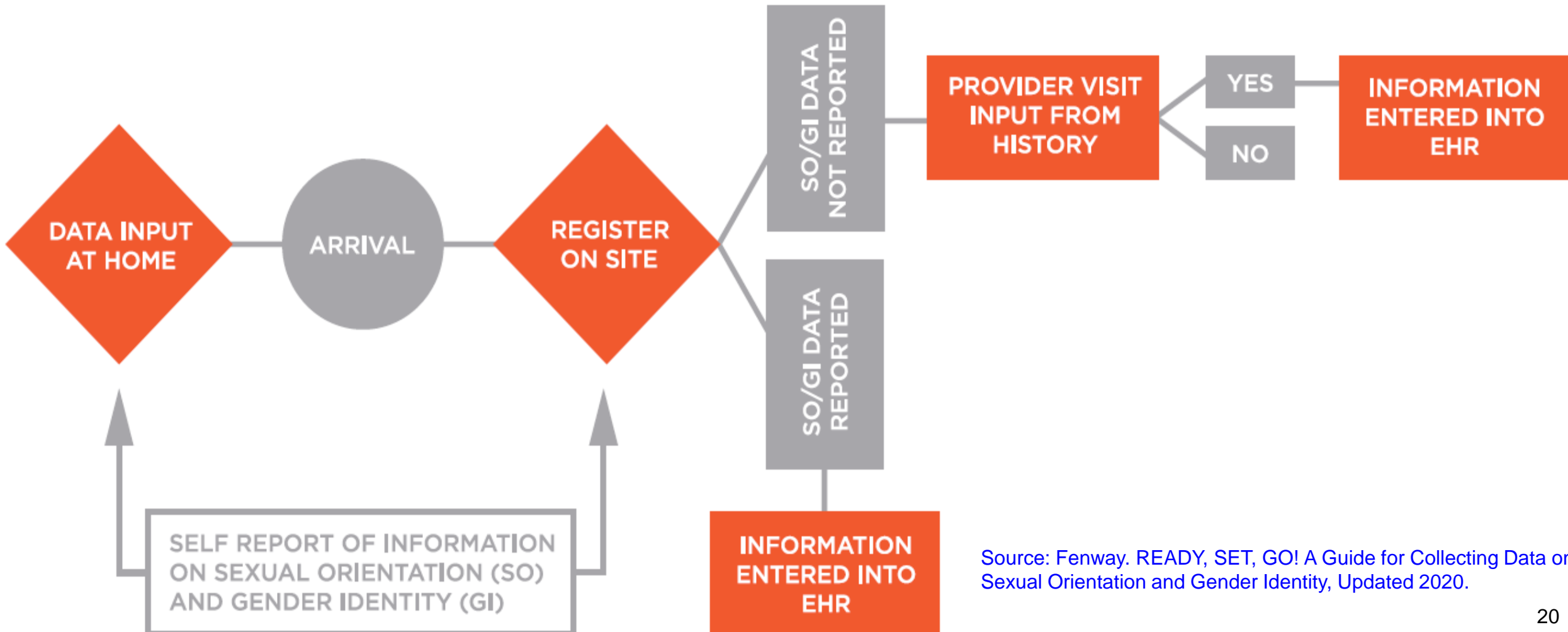
Source: Fenway. READY, SET, GO! A Guide for Collecting Data on Sexual Orientation and Gender Identity, Updated 2020.

4. What's in the action plan? … *Action 4*

1. Envisage an equity- and SGM-oriented health system vision and goal
2. Engage and partner with organizations and communities to modernize GSSO information practices to meet SGM needs
3. Establish GSSO terminology for patient care, health system use and research
4. **Enable EHRs to collect, use, exchange and reuse standardized GSSO data**
5. Integrate and tailor GSSO data collection with organizational structures, policies, use cases and workflow processes
6. Educate & train staff to provide culturally competent and safe care, and educate patients to understand need
7. Establish a central hub to coordinate this action plan over time and continue national conversation as next step

University of Victoria

CIHR IRSC | Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

This project has been funded through the CIHR Institute of Gender and Health

4. What's in the action plan? … *Action 4*

1. Envisage an equity- and SGM-oriented health system vision and goal
2. Engage and partner with organizations and communities to modernize GSSO information practices to meet SGM needs
3. Establish GSSO terminology for patient care, health system use and research
4. Enable EHRs to collect, use, exchange and reuse standardized GSSO data
   - ➢ Data fields and terminology
   - ➢ Interfaces for inputs/outputs
   - ➢ Security and privacy
   - ➢ Data quality
   - ➢ Decision support rules
   - ➢ IT support
   - ➢ Governance
   - ➢ Implementation options

4. What's in the action plan? … *Action 4 Examples*

1. Envisage an equity- and SGM-oriented health system vision and goal
2. Engage and partner with organizations and communities to modernize GSSO information practices to meet SGM needs
3. Establish GSSO terminology for patient care, health system use and research
4. Enable EHRs to collect, use, exchange and reuse standardized GSSO data
   - ➢ Data fields and terminology
   - ➢ Interfaces for inputs/outputs
   - ➢ Security and privacy
   - ➢ Data quality
   - ➢ Decision support rules
   - ➢ IT support
   - ➢ Governance
   - ➢ Implementation options
   - ➢ Examples from Fenway Health …

University of Victoria

CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada
This project has been funded through the CIHR Institute of Gender and Health

Current practice: Registration screen

Current practice: Registration screen

Source: Keuroghlian AS. Fenway Institute. SOGI Data Collection presentation Jun 9, 2020. .

EHR Form: Organ Inventory

Organ Inventory

BREAST
- *Congenital Absence* ☐
- *Chest Reconstruction* ☐
- *Bilateral Mastectomy* ☐
- *Unilateral Mastectomy, R* ☐
- *Unilateral Mastectomy, L* ☐
- *Breast Augment/Implant(s)* ☐

CERVIX
- *Congenital Absence* ☐

OVARY
- *Bilateral Salpingo-Oophorectomy* ☐ ✓
- *Unilateral Salpingo-Oophorectomy, R* ☐
- *Unilateral Salpingo-Oophorectomy, L* ☐

PENIS
- *Phalloplasty/Metoidioplasty/Penile Transplant* ☐
- *Erectile Device* ☐

PROSTATE
- *Prostatectomy* ☐

TESTIS
- *Testicular Implant(s)* ☐

URETHRA
- *Urethral Lengthening* ☐

UTERUS
- *Hysterectomy - Cervix Removed* ☐
- *Hysterectomy - Cervix Remains* ☐

VAGINA
- *Colpocleisis - Closure of the Vagina* ☐
- *Vaginoplasty* ☐

Prev Form (Ctrl+PgUp)   Next Form (Ctrl+PgDn)

# Clinical Decision Support (CDS)/ Health Maintenance

Current Variables:

- Sex
- Age
- Problems/Disease Conditions
    - e.g. Diabetes
- Medications
    - e.g. Coumadin
- Observations
    - e.g. Blood Pressure> 220

Recommended Additional Variables:

- Sexual Orientation
- Gender Identity
- Sex Assigned at Birth
- Anatomical Inventory

Decision Support/Health Maintenance

Sex=Male
Age = 52 yo
Sex assigned
at birth=Female

Anatomical Inventory
☑ Cervix
☑ Vagina
☑ Uterus
☑ Ovaries
☑ Breasts
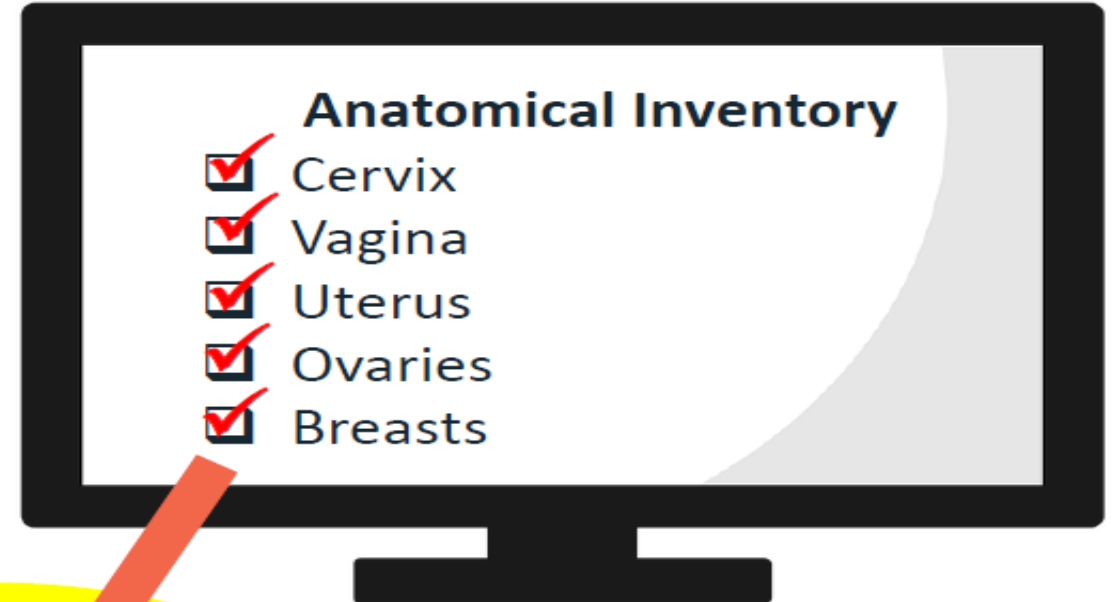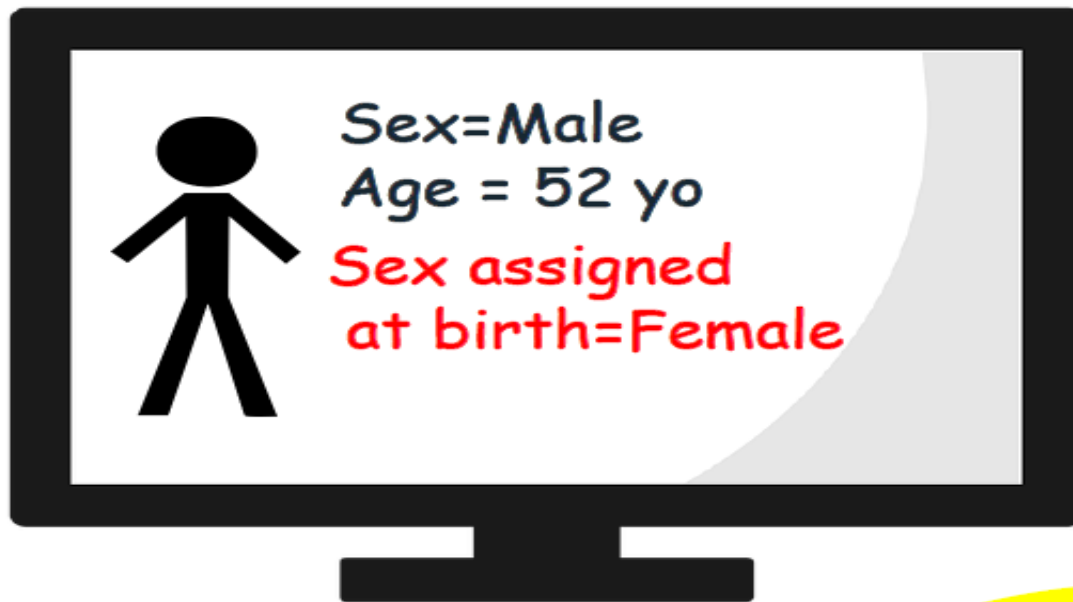
Patient Due For:
- **Cervical Pap Smear**
- **Mammogram**
- **????????**

5. What's the next steps

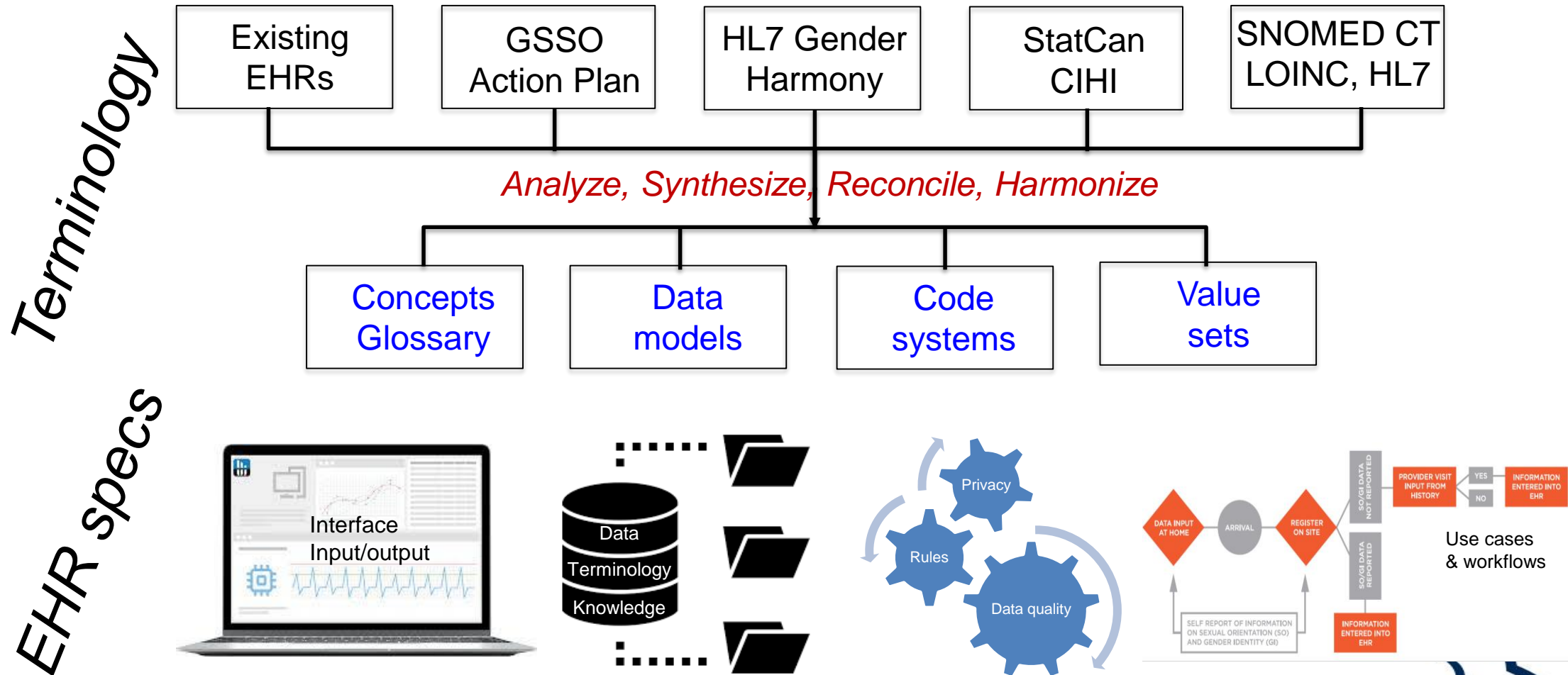➤ *CIHR planning grant knowledge translation outputs*
  - ✓ Lau et al. Rapid review of GSSO documentation in EHRs. *JAMIA* 2020
  - ✓ Lau et al. Environmental scan of sex and gender in EHRs – Analysis of public info sources. *JMIR* 2020
  - ✓ Davison et al. Culturally competent GSSO info practices in EHRs. *JMIR Medical Informatics* 2021
  - ✓ Action plan infographics, summary and full reports – Infoway Sex-Gender Working Group website
  - ▪ Commentaries, abstracts, blogs, special issues, presentations, interviews …

➤ *MSFHR REACH grant by Dr. Karen Courtney => Mar 2021 …*
  - ▪ Share previous findings
  - ▪ Develop KT tools for applying action plan in different contexts
  - ▪ Develop an Implementation Strategies Guidebook
  - ▪ => GSSO Terminology, EHR specifications, policies & practice, implementation settings

5. What's the next steps …. *Terminology and EHR*

Terminology

Existing EHRs	GSSO Action Plan	HL7 Gender Harmony	StatCan CIHI	SNOMED CT LOINC, HL7

Analyze, Synthesize, Reconcile, Harmonize

Concepts Glossary	Data models	Code systems	Value sets

EHR specs

Interface Input/output

Data
Terminology
Knowledge

Privacy
Rules
Data quality

Use cases & workflows

30

Selected References

1. Abel L, et al. Improved patient engagement for LGBT populations. Journal of AHIMA 2017; 88(3):34-9. -link

2. Canada Health Infoway. Sex and Gender Working Group - link

3. Canada Health Infoway. GSSO Action Plan Infographic, Summary and Full Reports – link

4. Davison K, Queen R, Lau F, Antonio M. Culturally competent gender, sex, and sexual orientation information practices and electronic health records: Rapid review. *JMIR Medical Informatics* 2021; 9(2). -link

5. HL7 International. *HL7 Informative Document: Gender Harmony – Modeling Sex and Gender Representation, Release 1. Sponsored by HL7 Vocabulary Work Group.* -link

6. House of Commons Canada. The Health of LGBTQIA2 Communities in Canada – Report of the Standing Committee on Health, June 2019. -link

7. Lau F, Antonio M, Davison K, Queen R, Devor A. A rapid review of gender, sex and sexual orientation documentation in EHRs. *JAMIA* 2020; 27(11):1174-83. -link

8. Lau F, Antonio M, Davison K, Queen R, Bryski K. An environmental scan of sex and gender in electronic health records: Analysis of public information sources. JMIR 2020; 22(11). -link

9. Menard FP, Prokopenko E. Sexual Orientation and Gender in Canada's Statistical System presentation, Feb 23, 2021. Statistics Canada –link

10. ONC Interoperability Standards Advisory. Section I: Vocabulary/Code Set//Terminology Standards. SOGI. link

11. Treasury Board of Canada Secretariat. Modernizing the Government of Canada's Sex and Gender Information Practices: summary report, April 8, 2019. -link

Questions? Comments?