

# BC Gender, Sex and Sexual Orientation Standards

W.L. Clifford, OBC, MD, FCFP

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# GSSO Context

- Common misunderstandings about difference between sex and gender concepts
- Limited functionality in health records to distinguish and effectively use the concepts
- Misunderstandings and limited functionality placing non-cisgender individuals at risk for disrespectful and suboptimal care.
- Current system cannot provide effective, comprehensive disaggregated information to identify disparities and address inequities in the context of GSSO

The value domain for Gender Identity consists of the following values:

- Male
- Female
- Intersex
- Indeterminate
- Other
- Person prefers not to say
- Unknown / Inadequately Described



# BC GSSO Components

Demographic/Administrative use – broad collection of gender, chosen name, pronouns and sex reported at birth for:

- Identification
- General clinical use
- Accommodation of existing ambiguous data

Support for clinical requirements:

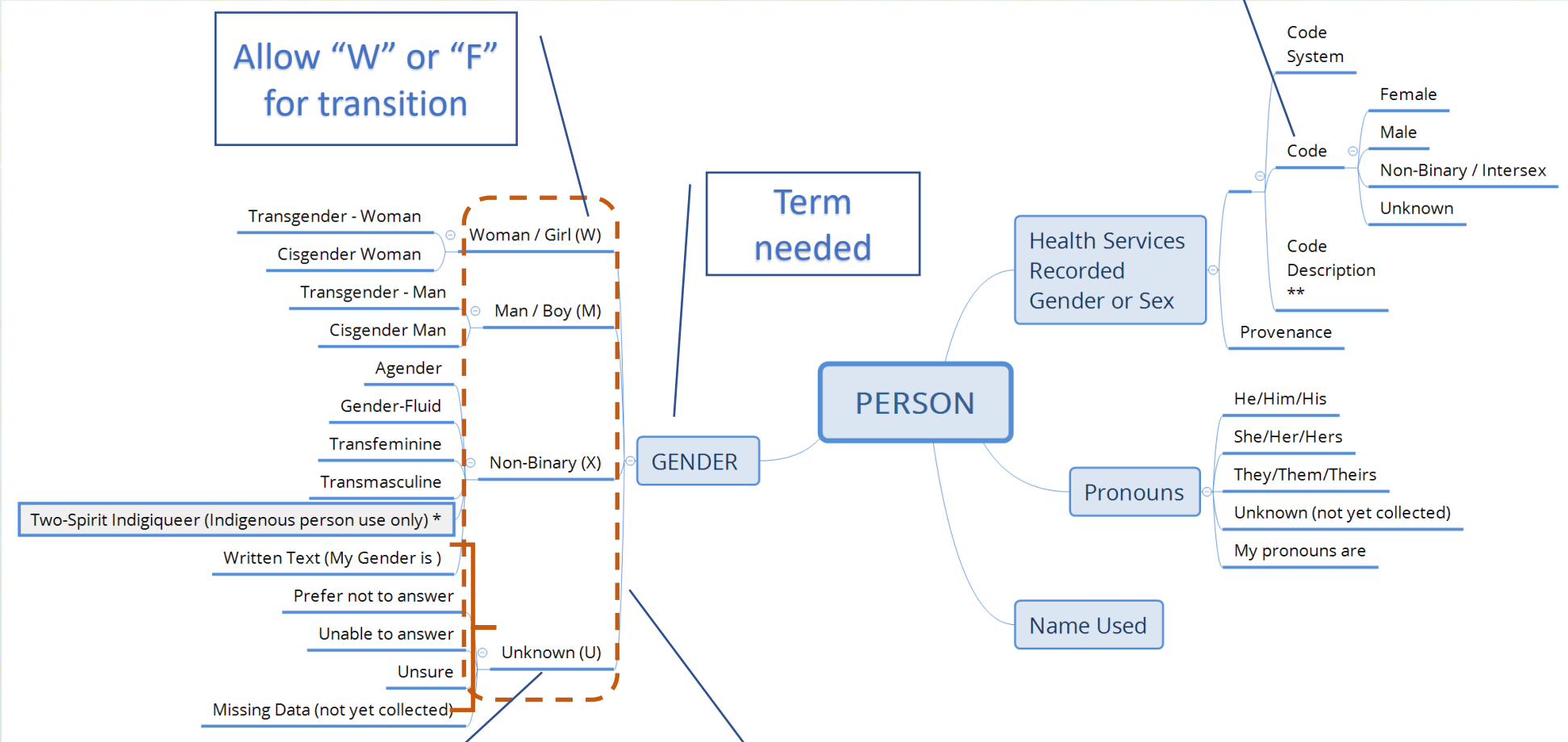
- Gender identity
- Clinically relevant sex related information
  - Anatomy
  - Hormone medications
  - Surgical procedures
- Sexual orientation
- Worries and negative experiences related to gender and sexual identities

# Gender Model (Demographics)

Any of the markers for sex and gender

Allow "W" or "F" for transition

Term needed



- Null Flavors**
- Missing Data – NI
  - Prefers not to answer – ASKU
  - Unable to answer – NASK
  - Unsure - OTH

Scope of demographics / administration

Health Services Recorded Gender or Sex

Pronouns

Name Used

- Code System
- Female
  - Male
  - Non-Binary / Intersex
  - Unknown

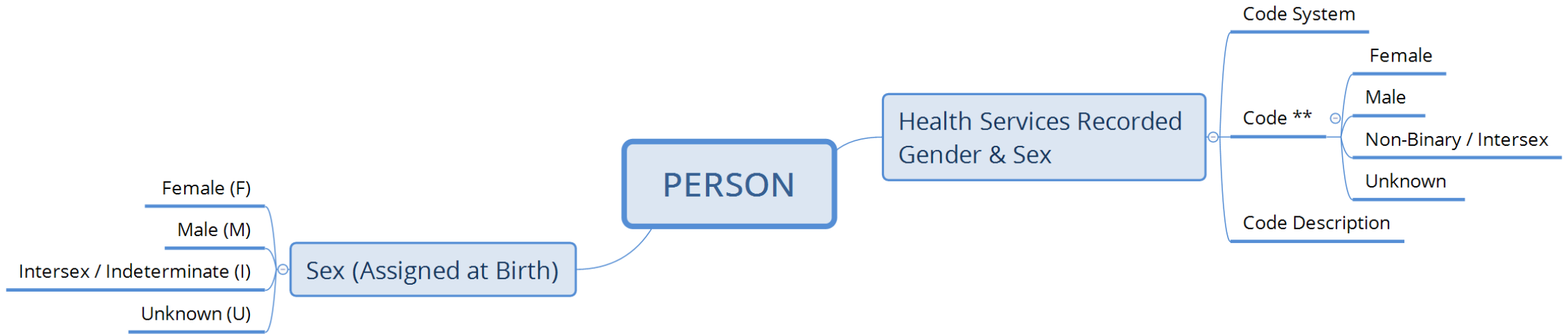
- Code Description \*\*
- Provenance

- He/Him/His
- She/Her/Hers
- They/Them/Theirs
- Unknown (not yet collected)
- My pronouns are

# Gender - Demographics

- A gender identity the person is willing to disclose for purposes of identification and other administrative aspects. Need a term distinct from administrative gender (to avoid the baggage associated with that term). Possible synonyms:
  - “Recorded gender”
  - “Gender used”
  - “Gender”
- Two step self identification
  - “what gender would like to be identified as?” (versus “what gender do you identify as?”) – or simply “What is your gender?”
- Require FHIR specifications for Health Services Recorded Gender or Sex

# Sex Model (Demographics)



## Null Flavors

- Asked, but unknown
- Not asked
- Unknown

# Clinical Concepts

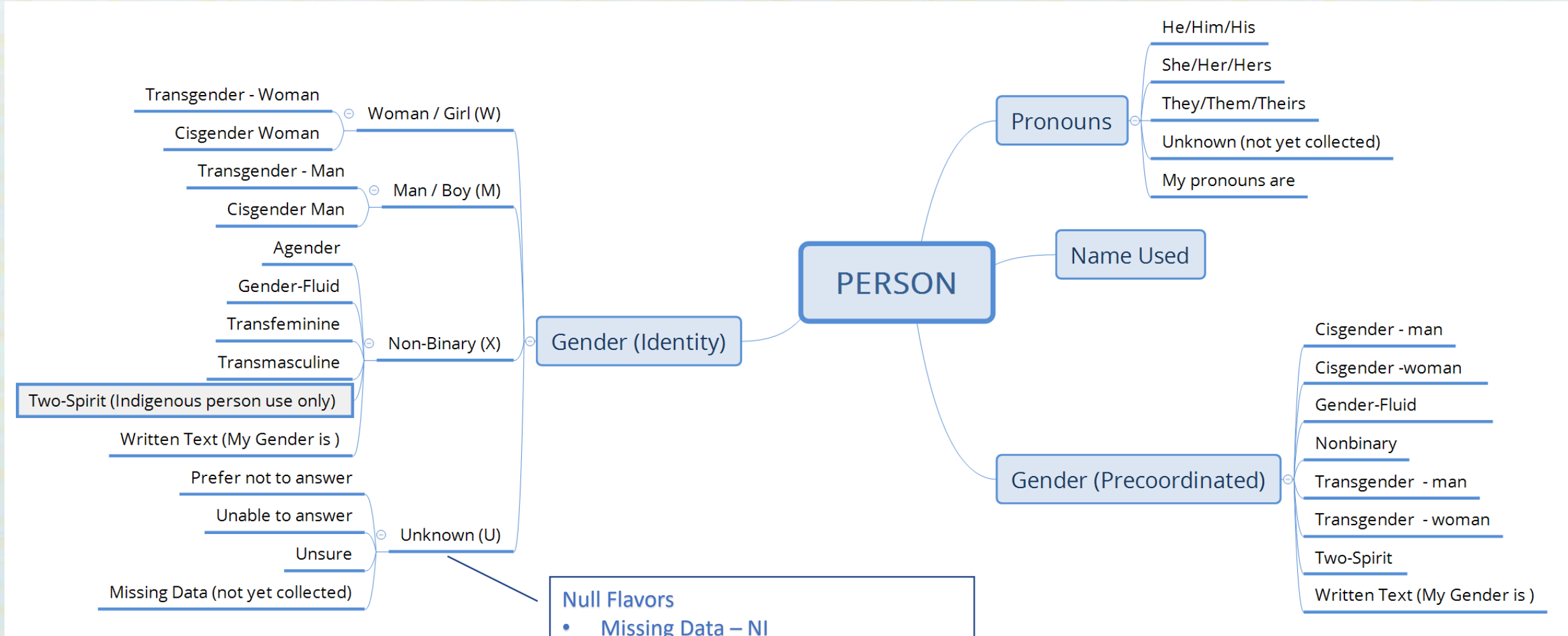
## Gender

- Gender identity (should never be inferred). May be different than demographic gender
- Gender expression
- Pre-coordinated or post-coordinated gender e.g., Transgender man (can be inferred from current gender and sex assigned at birth)

## Sex

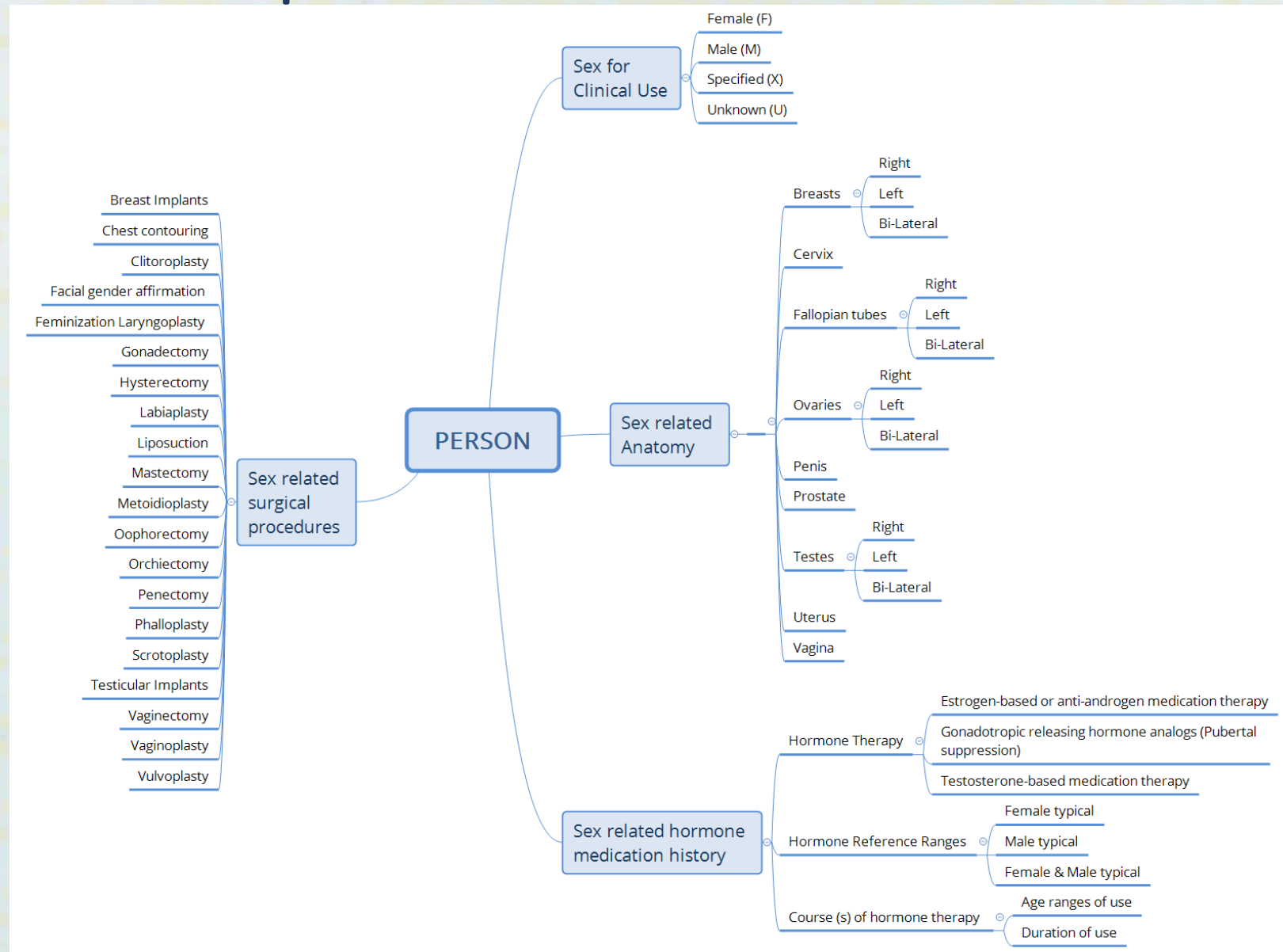
- Sex for clinical use - context specific
- Sex related anatomy - cannot necessarily infer anatomy from recorded procedures – may not have the required history documented and non-surgical factors can affect anatomy e.g., trauma, congenital
- Sex related surgical procedures - sometimes can infer anatomy from surgical procedures e.g., total hysterectomy likely (but not always) means absence of cervix)
- Sex related hormone medication treatment

# Gender Identity Model



- Null Flavors**
- Missing Data – NI
  - Prefers not to answer – ASKU
  - Unable to answer – NASK
  - Unsure - OTH

# Clinical Sex Conceptual Framework



# BC Sex Related Value Sets - Snippets

**Note(s):** This list is not exhaustive; SNOMED-CT can be used to provide more detail such as describe congenital absence of an organ:

Organ Concept	Code/display – Present	Code/display – Absent
Breasts	290053009 - Breast present 449844005 - Breast prosthesis in situ	723025005 - Bilateral acquired absence of breast 721551005 - Acquired absence of breast
Cervix	289755002 - Uterine cervix present	248911005 - Uterine cervix absent
Fallopian tubes	289832005 - Fallopian tube present	289833000 - Fallopian tube absent 237052004 - Acquired absence of fallopian tube
Ovaries	289835007 - Ovary present	723172008 - Bilateral acquired absence of ovary

## 10.3 Sex Related Hormone Medication History

The digital health system medication list should include medications of all types including sex related hormone therapy. Such a list should include the effective period for the medications (i.e., stop and start dates), dose, indication and other elements of a medication order or statement. By using the associated drug class, it is possible to group for viewing or exchange in a document, drugs in the following groups:

Drug Group	ATC code	Description
Estrogen-based or anti-androgen medication therapy	G03C G03H	Present or past estrogen-based hormone therapy (or nonprescribed medications).
Gonadotropic releasing hormone analogs (Pubertal suppression)	H01CA	Present or past use of puberty suppressing medications.
Testosterone-based medication therapy	G03B	Present or past use of testosterone-based hormone therapy (or nonprescribed medications).

## 10.4 Sex Related Surgical Procedures Value Set

A sex related surgical inventory contains common treatments and procedures which should be included in the medical or surgical history of all patients regardless of gender.

The following non-exhaustive list of procedures should be un-coupled from any gender-coded marker.

Procedure	SNOMED-CT	Description
Breast construction	172067003 Breast prosthesis operation (procedure) 52852000 Insertion of bilateral breast prostheses (procedure)	Procedure of prosthesis to change the s
Chest contouring	33496007 -Reconstruction of breast (procedure) 836272003 Gender confirmation top surgery (procedure)	Procedures 1 tissue and cr sculpted che also include
Facial surgery	62996004 Reconstruction of facial bones (procedure) 77419007 Reduction osteoplasty of facial bones (procedure) 119863003 Lip reconstruction (procedure) 232470004 Reconstruction of nose (procedure)	Procedures 1 the facial bo forehead, nc surrounding lips.

## 10.5 Observations related to Drug Therapy or Surgical Procedures

Observation Description (recommended)	Code	SNOMED-CT Description
Gender affirming surgery	SCT 719670005	Gender affirming surgery (SYN)
Gender affirming top surgery	SCT 836272003	Gender affirming top surgery (SYN)
Gender affirming bottom surgery	SCT 836273008	Gender affirming bottom surgery (SYN)

**Documenting sex related hormone classes of drug therapy (in referral letters, sex for clinical use statements etc.):**

Term	Code	Description
Androgen deprivation therapy	SCT 707266006	Androgen antagonists such as spironolactone, cyproterone acetate, 5-alpha reductase inhibitors, GnRH agonists and antagonists
Testosterone replacement therapy	SCT 724163007	Hormone therapy with testosterone
Estrogen hormone therapy	SCT 243125009	Hormone therapy with estrogens
Progestogen therapy	SCT 243126005	Hormone therapy with progestins

# BC Sexual Orientation Value Set

Concept	Code	Description
Asexual	SCT 765288000   Sexually attracted to neither male nor female sex (finding).	Person who feels little to no sexual attraction.
Bisexual	SCT 42035005   Bisexual (finding)	Person who is sexually or romantically attracted to those of the same gender and to those of one or more genders.
Choose not to disclose	HL7 NullFlavor ASKU	People who when asked, chose not to disclose
Gay	SCT 38628009   Homosexual (finding)	Person who is sexually and/or romantically attracted to people of the same gender.
Heterosexual	SCT 20430005   Heterosexual (finding)	Person who identifies as one gender and is mainly attracted to people of the other gender.
Lesbian	SCT 89217008   Female homosexual (finding)**	Person, usually a female/ woman who is sexually or romantically attracted to people of the same gender.
Not asked	HL7 NullFlavor NASK	Person was not asked for collection of this information.
Something else	HL7 NullFlavor OTH	People who identify their sexual orientation as something other than the categories provided (e.g., asexual, pansexual, queer).
Unsure	SCT 1064711000000108   Undecided about sexual orientation (finding) HL7 NullFlavor UNK	People who are uncertain about their sexual orientation.

Source: [Action Plan to Modernize GSSO Information Practices in Canadian EHRs](#).

\*\* Requesting change of SNOMED-CT preferred term to "Lesbian"

# Documenting Negative Experiences Related to Gender Identity & Sexual Orientation – sample of new SCT concepts

Term	Code	Description
Negative experiences related to health care system in relationship to gender identity	SCT – to be obtained	Synonym – Experiences related to gender-based discrimination in health care; Experiences related to cisnormative bias in health care; Experiences related to sexism in health care; Experiences related to misogyny in health care; Experiences related to genderism in health care; Experiences related to cissexism in health care; Experiences related to cisnormativity in health care; Experiences related to masculonormativity in health care
Negative experiences online related to gender identity	SCT – to be obtained	Synonym – Experiences online abusive behaviour related to gender identity, Experiences gender-identity-related cyber-bullying
Negative experiences related to gender identity	SCT - to be obtained	Synonyms – Experiences transphobia; Experiences genderphobia; Experiences enbyphobia; experiences misogyny; Experiences misandry; Experiences sexism; Experiences genderism; Experiences binarism; Experiences cissexism; Experiences cisgenderism; Experiences exorsexism
Finding related to misgendering or deadnaming	SCT – to be obtained	Synonym -- Finding related to mis-gendering or dead-naming
Worries related to outward visibility of gender identity	SCT - to be obtained	Synonym – Worries related to gender expression; Worries related to gender nonconformity; Worries related to gender non-conformity
Worries about being open about gender identity	SCT - to be obtained	Synonym - Worries about coming out, gender identity

Terms will be added to the BC health concerns subset

# GSSO Implementation

## Participation in or being informed by national and international groups

- CIHI/CHI
- Gravity project (US)
- WPATH
- HL7
- US ONC

## Feedback from partners

- Trans Care BC
- University of Victoria
- GSSO Terminology Working Group - CHI

## Clinical & Health Information Management business rules / implementation guides – e.g.

- Sex and gender are two distinct concepts and should not be used interchangeably
- Gender data should be collected and displayed by default
- Gender should be identified by the patient and should not be assumed or assigned by a health care provider
- Sex for clinical use should be documented when clinically required
- Sex recorded at birth or sex for clinical use should be used for all laboratory and imaging requisitions

# GSSO Implementation Continued

## Demographic changes

- Small change to current data model – 2 distinct data elements instead of one
- Big change to small component of workflow
- Requires change to messaging standards for nearly all documents

## Clinical changes

- Drug orders and medication statements (to understand hormonal treatment)
- Medical imaging and laboratory test orders
- Referrals (order for consult, services)
- Operative procedures (orders, procedural reports, history of)
- Observation value sets including health concerns and findings

## Next steps

- MVP process with stakeholders
- Resourcing for change management / orchestration
- Clinical guidelines

# Short List of Systems in BC Affected by These Standards

System	GSSO
EMRs & health authority EHRs (acute and community)	✓
EMPI and interface	✓
Vital Statistics	✓
Pharmanet	✓
Care Connect / PLIS	✓
Panorama	✓
Surgical patient registry	✓
BC MSP Teleplan	✓
CDX/Excelleris/CIX/POI	✓
Research interfaces (e.g., those using CDISC or equivalent)	✓