BRITISH COLUMBIA

Ministry of Health

British Columbia
Health Information Standards

Gender, Sex and Sexual Orientation (GSSO) Health Information Standard and Guidance

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1.0 Acknowledgements

The Conformance, Integration, and Standards (CIS) in the Health Sector Information Management/Information Technology (HSIMIT) Division of the BC Ministry of Health is grateful to the individuals and organizations that contributed to the development of this document.

1.1. Territorial Acknowledgement

We acknowledge with respect and gratitude that this standard was developed on the territory of the Lək'ʷəŋən peoples, and recognize the Songhees, Esquimalt (Xwsepsum), and W̱SÁNEĆ Nations whose deep connections with this land continue to this day.

We also gratefully acknowledge the contributions of the following people and organizations to this standard:

1.2. Clinical and Informatics Advisors

- William Clifford OBC, BMedSci, MScF, MD, FCFP
- Kelly Davison MN, MSc, RN, CPMHN(C), CTSS

1.3. Contributing Organizations

- Canada Health Infoway - Sex-Gender Working Group
- Canadian Institute for Health Information
- First Nations Health Authority
- Trans Care BC
- University of Victoria GSSO Research Team
- Centre for Gender and Sexual Health Equity

1.4. Governance

- Former Health Information Standards Standing Committee (HISSC)
- Digital Health Standards Office (DHSO)
- Office of the Chief Information Officer (OCIO)

2.0 Introduction

The BC Ministry of Health has produced a gender, sex, and sexual orientation (GSSO) health information systems (HIS) standard and guidance ('the Standard and Guide') to advance the key priority of inclusive, equitable, and quality healthcare for all people. This Standard and Guide serves as a plain language reference document and includes a widely applicable common standard, optional expansions to the common standard as well as evidence-based rationale, guidance for implementation and other useful information and resources. Explanatory figures are provided to support visual learners and for quick reference.

2.1. Purpose of this Standard and Guidance

Our aim with this Standard and Guide is to support a consistent approach to the ongoing modernization of GSSO information practices in BC healthcare, and to support improved delivery of health programs and services by:

- Providing a framework, concepts, definitions, and guidance for the selection of technical artefacts such as concepts from controlled medical vocabularies/health terminology standards (e.g., SNOMED CT CA Edition, LOINC) and code values from health information exchange standards (i.e., HL7 International) which are used to share data between HIS.

- Supporting quality, affirming and culturally safe care for 2SQTBIMIPOC[1] and improved health outcomes through evidence-based design and implementation guidance.

    - This includes the inclusion of data elements that can be used to address Indigenous-specific racism and support the outcome of cultural safety (i.e., Name Used). Laying the foundation for improved visibility into 2SQTBIMIPOC data collection and definitions for gender identity and sexual orientation and acts as a policy to guide providers to use patient chosen names and pronouns, while ensuring protections for Sex at Birth data.

- Modernizing principles, policies, processes, and information practices that include defining, collecting, organizing, exchanging, and using GSSO concepts in HIS which include digital health information systems (DHIS) such as electronic health records (EHRs), electronic medical records (EMRs), and patient portals.

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[1] 2SQTBIMIPOC stands for Two-Spirit, Queer, Trans, Black, Indigenous, Multi-Racial, People of Colour and is used in this standard in the manner described by the Health Equity Collaborative in their publication *Believe Me: Identifying Barriers to Health Equity for Sexual and Gender Diverse Communities in British Columbia.*

- Promoting the integration of a wide range of social services (e.g., public health, population health, epidemiology, cancer staging and registry).
- Illustrating how modernized gender and sex information practices can help meet the information needs of a wide range of users within healthcare.
- Clarifying practices for consistent and accurate representation, collection and use of gender and sex health information.
- Outlining minimum (common), expanded and exceptional GSSO data collection standards.

2.2. Release-specific Information

There have been many developments in the provincial, national and international standards since the release of the March 2023 Standard and Guide. Where possible, we have harmonized this standard with national and international standards and have incorporated feedback received on the March 2023 version. Changes in the July 2024 Standard and Guide include:

- Added Canadian descriptions to SNOMED CT GSSO concepts
- Alignment with the CIHI Pan-Canadian Health Data Content Framework
- Alignment with the HL7 Cross Paradigm Implementation Guide: Gender Harmony—Sex and Gender Representation, Edition 1
- Improved guidance for Indigenous Gender Identity content that is by and for Indigenous Peoples
- Refined data element name Sex Assigned at Birth to Sex at Birth
- Refined data element name Administrative Gender to Gender Used
- Refined data element name Pronouns to Personal Pronouns
- Added definitions for sexual orientation
- Refined definitions for sex and gender concepts
- Refined definitions for exceptional value options
- Developed subsets to support adoption
- Added additional evidence, guidance and usage notes

- Improved diagrammatic representation
- Restructured the standard according to data element to improve readability

2.3. Target Audience

The audience for this Standard and Guide includes those individuals and organizations dedicated to designing DHIS that support affirming person- and family-centered healthcare for all people. It has been prepared for systems architects, clinical informatics specialists, clinicians, data scientists, database administrators and systems designers, health information professionals, researchers, and the public.

3.0 Background

This Standard and Guide is intended to support quality healthcare for all people, regardless of race, country of origin, sex, sexual orientation, gender identity, or socioeconomic status. It provides important guidance on the collection and use of information that is important for providing affirming, culturally safe and culturally sensitive person, and family-centered care to British Columbians.

Fundamentally, this Standard and Guide is designed to support trauma-informed care, and addresses barriers to access such as misnaming, misgendering, outing and missed opportunities for preventive screening, all of which are avoidable harms that contribute to health inequities.

It is expected that inclusive healthcare can be achieved by applying a consistent, respectful approach to representing, documenting, and using GSSO information, electronic or otherwise, in direct patient care and administration.

3.1. Rationale

In the absence of standardized GSSO data elements and value options, GSSO information quality in DHIS is inadequate and contributes to health inequities. (1)

Most DHIS are unable to unambiguously capture gender and sex information. (2)

In many systems there is a single field labelled either “Gender” or “Sex” with only female, male, or unknown options. (2)

Misrepresentation through conflation or aggregation of sex and gender concepts, and misrepresentation by limitation of value options to choices that unnecessarily reinforce a gender and sex binary have made gender minorities largely invisible in DHIS. (3–5)

Invisibility has negative impacts to access to and delivery of quality healthcare, as well as our ability to accurately understand correlations between sex, gender, gender identity, sexual orientation, and patient health needs and outcomes through analytics. (5,6)

When clinicians have access to accurate information about a person’s gender such as their pronouns, the name they wish to use, and their gender identity, negative experiences of healthcare related to misnaming, misgendering and accidentally “outing” patients can be avoided. (1,5,7,8)

3.2. Context

Expert clinicians, health information professionals, researchers, standards development organizations, and the broader community of British Columbians and Canadians with lived and living experience have contributed to the development of this Standard and Guide.

Sex and gender data may be collected for the identification of disparity and inequity in the broader health system, and to provide optimal healthcare services and reporting.

In July 2016, the BC Human Rights Code was amended to include protections for “gender identity or expression.”

In February 2018, the BC Public Service implemented Gender-Based Analysis Plus (GBA+) as a requirement for policy, program, and legislative processes. Through GBA+, the province recognizes the importance of how diverse groups of people may experience policies, programs, and initiatives and that by updating both sex and gender terminology, and formally integrating it into clinical care, we can positively influence health outcomes for gender-diverse populations.

Since November 2018, British Columbians who do not identify as male or female have had the choice to display an “X” as an option in the “gender” field of their BC-issued driver’s license, identity card, birth certificate and BC Services Card. In recognition of the challenges patient’s experienced with marker updates, further legislative changes were made in BC that transitioned the province to a non-medical model of gender identification allowing residents to change the gender on their birth certificate without confirmation by a physician or psychologist.

In September 2020, BC’s Office of the Human Rights Commissioner (BCOHRC) issued recommendations for the provincial government, titled Disaggregated Demographic Data Collection in BC: The Grandmother Perspective. This document outlines how to collect and use disaggregated gender and ethnicity-based data to reveal systemic racism and inequities in our province. The BCOHRC report offers a framework for disaggregated data collection that includes defining the purpose of the project, setting up a respectful process and defining the scope and limitations of data collection tools within the community.

3.2.1. Government of Canada

The Government of Canada has also enhanced its recognition of gender identity diversity:

- In July 2017, the Government of Canada added gender identity or expression to the Canadian Human Rights Act and the Criminal Code of Canada, which made it necessary to distinguish the concepts of sex and gender.
- In mid-2018, the Treasury Board of Canada Secretariat and the Department of Justice Canada presented a report with recommendations on ways to modernize how the Government of Canada handles information on sex and gender, and Statistics Canada released sex at birth and gender variables and classifications in order to better reflect how Canadians describe themselves.
- By February 2021, the Government of Canada and Statistics Canada started consultations with stakeholders to review proposed amendments to the gender standard.
- In November of 2021, Statistics Canada released data on Classification of cisgender, transgender and nonbinary people in Canada.

3.2.2. Standards Developments

In November 2019, the Canada Health Infoway's Sex and Gender Working Group was convened with the aim of modernizing gender, sex, and sexual orientation (GSSO) information practices in Canada.

In January 2020, with a planning grant from the Canadian Institutes of Health Research (CIHR)[2] a team of researchers established a coalition of communities and organizations across Canada to co-create an action plan to modernize GSSO information practices in EHR systems in Canada.

This Standard and Guide draws on the Action Plan and also draws heavily on content from the Office of the Chief Information Officer's *Guidelines to the Gender Identity and Sex Information Data Standard* with minor modifications ensuring relevance to the healthcare sector.

The Action Plan, which outlines the plan to modernize GSSO information practices for supporting and integrating gender and sex data collection in Canadian EHRs, was published in 2021 with the aim of advancing health equity for 2SLGBTQ+ people. (3)

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[2] CIHR. Planning and Dissemination Grants: Sponsor Description: CIHR – Institute of Gender and Health. Summary/Relevance. Aug 7, 2019.

Development and publication of the Action Plan coincided with the development and publication of the HL7 International Gender Harmony Model, with which this standard is harmonized.

In 2023, HL7 International, with input from Canada Health Infoway's Sex-and Gender Working Group and an international, transdisciplinary cohort of contributors, published the HL7 Cross Paradigm Implementation Guide: Gender Harmony—Sex and Gender Representation, Edition 1, which represents a refinement of the content outline in the HL7 Gender Harmony Model and provides guidance for the implementation of the Gender Harmony Model across HL7 messaging paradigms, some of which are used widely in BC (i.e., HL7 Version 2).

In early 2024, the Canadian Institute for Health Information (CIHI) engaged Canadians in a review of the proposed Pan-Canadian Health Data Content Framework, which includes GSSO data that are harmonized with existing standards. The Ministry continues to collaborate with pan-Canadian Health Organization partners such as CIHI and Canada Health Infoway to ensure that standards are inclusive, evidence-based and support clinical requirements effectively.

3.3. Protection of Privacy

Gender and sex information are personal identity information and must therefore only be collected as authorized under the *Freedom of Information and Protection of Privacy Act* (FOIPPA) or under the *Personal Information Protection Act* (PIPA).

Ministries, agencies, boards and commissions must have administrative controls in place to ensure that they collect the minimum amount of personal information necessary for the purpose, and that the information is directly related to an operating program or activity (e.g., gender-based analysis, health program and service delivery, research, operational decisions) as part of the *Core Policy and Procedures Manual*, specifically Chapter 12: Information Management and Information Technology Management.

3.3.1. Notification

Patients need to know and understand why personal information is being collected and how it will be used. Under FOIPPA and PIPA, government and non-government organizations must be able to clearly explain why the information is needed, and how it will be maintained and used. Where personal information is being collected as part of a survey, it is also important to explain why the information is helpful, and how it is maintained and used.

3.4. Ethics and Use

There are two key considerations when collecting personal information, including GSSO information:

- What are the ethical considerations around the collection of this personal information?
- Does the program or initiative have a legislated authority to collect, maintain, use, and/or disclose information?

3.4.1. Legislated Authority

GSSO information is personal identity information, and FOIPPA and PIPA legislation must be considered when gathering and managing such information. It is also important to note that there are limitations to what is outlined in legislation: it determines what can be done but does not typically provide guidance about how to do it.

This Standard and Guide is provided with the intent to adhere to the recommendations outlined by the BCOHRC in the report Disaggregated Demographic Data Collection in BC: The Grandmother Perspective.

Guidance:

The following questions may be helpful when considering whether or not to collect GSSO information beyond that which is needed for the clinical record:

- Is the information necessary for care or a clinical program or initiative?
- If the information will be analyzed, is it possible to analyze the information by Gender or Sex at Birth (e.g., is the group you are collecting information from too small for this kind of analysis, or is the group of a sufficient size for analysis)?
- Could this information be useful for informing programs, practices, and/or policies?
- How will this information benefit clinicians, the healthcare system or society?
- Could the information be harmful to specific communities (e.g., in development or resource allocation decisions, healthcare)?
- If the information could be used against specific communities, is it possible to avoid or prevent harmful usage?
- Could the collection of information be done in consultation or collaboration with representatives from the relevant communities?

3.4.2. Why are Ethical Considerations important?

The concept of ethics in health information standards is complex, but generally refers to what ought to be done when it comes to collecting, maintaining, using, and disclosing information. Ethics inform best practice, and ethics are not necessarily set out in legislation but are a key element that factors in work-related decisions of many types of healthcare staff, including those in the public service. (9)

This Standard and Guide, and the values of inclusivity and anti-discrimination that it embodies, align with the ethical codes developed for health professions including health information management professionals, nursing, and medicine. (10–12)

3.4.3. Minimizing Harm & Maximizing Benefit

It is for both legal and ethical reasons that we want to be mindful about collecting personal information to support a program or initiative. When we collect more information than what we need or can use, we can:

- increase the risk of harm (e.g., resurface stress or trauma in respondents);
- increase risk of inappropriate use of extra information; and
- decrease potential benefits of data use.

The importance of minimizing harm and maximizing the benefits of collected information cannot be overstated and is particularly important for vulnerable groups—including those who identify as nonbinary, Two-Spirit, Indigiqueer, transgender, or others who are gender diverse.

It is helpful to remember that healthcare workers are representatives of the broader health system. People who are in vulnerable groups and/or who are at-risk of marginalization often have a history of negative experiences with the health system. (1,4,5) For example, transgender and nonbinary people commonly report experiences of stigmatization and discrimination after disclosing their gender identities to healthcare providers. (8,13–17) As a result, some individuals may not trust how healthcare workers will maintain, share, and use this kind of data. Also, there may be discomfort in providing the information, especially if it does not appear to be relevant, or if the wording (e.g., survey question, intake form) does not follow best practice.

3.4.4. Small Numbers

When using GSSO data for analysis or decision-making, be cautious of the number of respondents. To determine if a survey group is too small, it is necessary to have a good understanding of that specific population and risks of identifiability. Risk-based de-identification[3] is a frequently recommended framework wherein contextual and data-related factors are considered to determine overall risk of re-identification. Generally, when sample sizes approach five individuals, it is especially important to use a formal approach to weigh survey needs against risks.[4]

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[3] De-Identification Guidelines for Structured Data. Information and Privacy Commissioner for Ontario, 2016

[4] The Definitive Guide to De-Identification. Privacy Analytics Whitepaper, 2017

3.4.5. De-identification, Storage and Disclosure

It is important to recognize that complex situations that cannot be addressed by these guidelines alone will arise. Organizations should consider whether it is necessary to tie the collected GSSO information to a specific individual. If not, organizations should consider de-identifying or anonymizing the collected information since doing so can mitigate the risk that personal information is associated to a specific individual.

Organizations should also consider whether the information can be collected in a way that is fully anonymous–such as not linking a person's name to their survey responses, and what level of security is warranted to protect the identifying information. Secure storage includes making sure that only people who need to see the information can access it, and that they access it in an appropriate way.

In most cases, public servants and people who work in healthcare do not have the authority to disclose GSSO information unless it is clinically relevant. For example, surveys or other reviews and reports should provide aggregated information, or information that has been anonymized in a way that prevents others from knowing who is being discussed. In other cases, a person's gender will need to be displayed on documents such as a driver license or passport. However, even when GSSO information is displayed for specific purposes, an organization still needs to protect the personal information it maintains in accordance with legislation and policy.

Scenario: A caseworker is caring for a minor who shares that they identify as transgender or nonbinary. If the minor has not disclosed their gender to the guardians (or disclosure is unclear), how should the caseworker refer to the minor when speaking to legal guardians?

Discussion: This situation is ethically complex. It requires balancing gender affirmation, consent to disclose (where disclosure can include using the minor's chosen pronouns with third parties), and legal guardians' information needs (e.g., to make informed healthcare decisions). Additional factors, including the minor's age, legal requirements, and professional guidelines also make it problematic to assert general guidelines on how to respond. In complex situations such as this, consult the standards/guidelines in your professional organization, regulatory body, and/or ministry for additional guidance. Some questions that may be helpful to ask yourself in situations such as this may include:

- Has the individual consented to their information being shared with others?
- Are there any limits to confidentiality in the collection, maintenance, use, and/or disclosure of this information (e.g., legislated requirements, display requirements)?
- What can be done to protect confidentiality and/or anonymity?
- If data will/may be shared with other services, how will it be shared?

3.5. Use of the Standard and Guidance

Use of the Standard and Guide must be considered in conjunction with:

- Corporate policies, standards and strategic direction issued by government, including the:
    - Standards of Conduct for BC Public Service Employees,
    - Draft Principles that Guide the Province's Relationship with Indigenous Peoples,
    - Province's Digital Principles, and
    - IM/IT policies and standards issued by Office of the Chief Information Officer; and
- Other forms of legislation that may apply to specific organizations (e.g., Health Authorities and/or Medical Associations) within government.

3.6. Scope

The scope of this Standard and Guide is limited to specifying the GSSO data elements that will enable consistency in BC's healthcare system.

These data elements include:

- Gender, including Gender Identity, and components of gender expression such as Pronouns, and Name to Use.
- Sex, including Sex at Birth, Sex Parameter for Clinical Use, sex-related anatomy, sex-related hormone and medication context artefacts, and sex-related surgical procedures.
- Sexual orientation. Nuanced aspects of sexual orientation including sexual identity, sexual attraction, and sexual behaviour are not included, although they may be relevant to clinical sexual health assessments.
- Administrative data elements such as Gender Used (Administrative Gender) and the Health Services Sex and Gender Marker.

This Standard and Guide does not:

- Necessitate or limit the collection of data that a health authority, health agency or the health ministry may require to fully support its programs or services.
- Instruct business programs on the use or storage of gender and sex data nor detail the specific business processes that support use of a standard in a specific system/application nor detailed technical specifications, such as field length and cardinality, which may be found in the respective application's technical documentation.
- Consider Titles and/or Honorifics (e.g., Dr., Mr., Mrs., Ms., Mx., Sir., Madam, etc.) as outlined in the guidelines for gender-inclusive writing or recommended style (i.e., Public Works and Government Services Canada, BC Ministry of Health Writing Guide, Translation Services Style Guide).

Indigenous Peoples' Information:

This Standard and Guide is not intended to instruct business programs on the collection, use or storage of GSSO information of Indigenous Peoples, or to provide guidance on how to engage with Indigenous Peoples or communities.

However, it is important to note that it remains incumbent on organizations to adhere to the principles of Ownership, Control, Access, and Permission (OCAP).

3.6.1. Controlled Medical Vocabularies and Health Terminology Standards

Many of the modern concepts required to support this Standard and Guide are either not available in health terminology standards or are currently specified in a manner that is considered to be outdated and offensive. (18,19).

Examples of this include SNOMED CT concepts that currently offer Fully Specified Names (FSNs) or synonyms (e.g., “Eunuchoidism,” “Feminism in boy”, “Masculinized female”, “Frigidity”, “Transvestism”, “Counseling for homosexuality”). Stigmatizing concepts such as these must not be used in DHIS because they are harmful(19) and we are currently working with standards development organizations to have them modernized or removed.

The terms intended for clinical use presented in this standard may therefore be incomplete, in the process of being modernized, or named as unencoded terms pending their incorporation or modification into controlled medical vocabularies, health terminology standards and code systems.

Work is currently underway locally, nationally, and internationally, to make such modifications to SNOMED CT, LOINC and other terminologies or ontologies so that they support the clinical requirements for respectful, affirming communication and accurate documentation. (3)

Furthermore, implementation of this Standard and Guide may allow for escape from common value set options to expanded options for richer expression of concepts and capture of more granular structured data. It is vital that users and system implementations are aware of the limits of acceptability in choice of terms because of the risk of harm associated with stigmatizing language. There are many resources available to inform language, including the BC Centre for Disease Control (BCCDC) Inclusive Language Guide. The value sets developed for this standard align with existing international standards, and underwent extensive review before publication.

4.0 Cultivating a Culture of Acceptance and Inclusion

The Standard of Conduct for BC Government Employees requires that employees provide courteous and equitable service to the public and that they treat each other with respect and dignity. As public servants, the language we use can allow us to promote a more just and inclusive society and lead through example, or it can signal to people that they or members of their community are not respected or do not belong. Repeatedly hearing language that implies that you should not be accepted or should be excluded can be distressing and can lead to dire outcomes.
Furthermore, the burden of constantly having to correct how someone addresses a person can be exhausting for them, and impacts physical and mental health. (1,4,13,17)

The following guidance is meant to expand on those policies and help employees behave in ways that ensure all people are respected, safe and made to feel welcome in our province.

4.1. Reduce Gendered Language

Gendered language is pervasive in our society. (20) Many of us were probably welcomed in school with familiar phrases such as "…. good morning, boys and girls," or "welcome, ladies and gentlemen." This is common language, but using it emphasizes that gender is the most important thing about the people with whom you are speaking and limits them to a gender binary. Repeated studies have found that emphasizing gender categories leads to increased tensions and harassment; we should instead look for ways to welcome all people. (20,21).

Helpful Hint(s):

You might also consider making it a practice to default using gender-neutral language when interacting with the public and your colleagues.

For example, say:

- "child" instead of daughter or son;
- "partner" instead of husband or wife;
- "folks" instead of "guys"; and
- "person who is pregnant" instead of "pregnant woman".

Referring to colleagues as being on "parental leave" rather than "maternity leave" or "paternity leave" is also more inclusive.

For example, when speaking to a large group, simply say:

- "Welcome," or
- "Good morning/afternoon/evening everyone."

These small but meaningful changes can help change the way you think about gender identity and ensure that you do not inadvertently exclude people that you are serving.

4.2. Use A Person's Pronouns and Name Used

In our everyday language we use pronouns in the place of names. Common pronouns include "he" and "she" as well as "they." Simply ask each patient what pronouns they use and in what contexts. For example, youth or adolescent patients may disclose and permit the use of nonbinary or neopronouns by healthcare staff in healthcare interactions but may not want this information shared with their parents. If you are unsure of a person's pronouns, it is acceptable to use "they" as a single-person pronoun (e.g., in a question like "What did they say?") until you can confirm the pronouns that should be used with the patient. It is important to use a person's identified pronouns both in their presence and when they are not in the room. For example, if you have an interaction with a patient and later, when talking to a colleague about the patient's file, you are unsure about their pronouns, use "they":

<u>Helpful Hint(s)</u>:

Avoid making assumptions about a person's pronouns based on how the person looks to you.

Not all people look a certain way or come from the same background, and they may not appear to visibly belong to a gender group.

Using the term "they" in both the singular and plural is considered acceptable grammar. (18)

- "They were experiencing issues with our online system and were unable to submit the application. I asked them if they could send it via email."

Listen carefully to what people ask for, including how they refer to themselves, the gender pronouns they use, and how they ask to be addressed. For example, if someone asks to not be referred to as a man, it is harmful to misgender them using the honorifics "Mr." or "Sir." The use of titles and honorifics such as these is discouraged because they are often gendered and increase the risk of misgendering or outing a patient.

4.3. When You Make a Mistake, Apologize and Move On

Mistakes happen. The best thing we can do is let the individual know you regret the mistake and will do better in future.(1) Make sure to do this in a way that doesn't draw more attention to the error or put someone on the spot. Use the opportunity to reflect on and manage your own biases, take accountability for your mistakes, and commit to correcting them in the future.

4.4. Understand Your Role as a Representative of the BC Public Service

How you say something is just as important as what you say. Be mindful of your facial expressions and body language so as not to inadvertently give the impression of being judgmental. The BC Public Service is committed to treating everyone with dignity and humanity by listening to their individual needs, establishing respectful relationships, showing compassion and sensitivity, and providing services in a way that respects all people.

Now that we have outlined the importance of language and inclusivity, we will move on to introducing the main content of the Standard and Guide.

5.0 GSSO Conceptual Framework and Information Model

The primary challenges related to GSSO information practices that this and other related standards attempt to address are conflation of administrative and clinical data elements, and conflation of sex and gender concepts in DHIS. This information is sometimes inaccurate and used by clinicians in providing care. Many DHIS have traditionally used administrative data elements for clinical purposes. (2) In turn, this has led to patient harm and barriers to healthcare access for some people who have had negative experiences in healthcare (1,4) which can result in avoidance of healthcare and missed opportunities for preventive screening. (1,5)

Modernizing GSSO information practices means separating administrative and clinical data elements, using them for their intended purpose, and specifying them to a sufficient degree to prevent and mitigate harms caused by outdated information practices.(3) It means ensuring that providers have ready access to the information they need about a person to communicate with them in an affirming manner, avoid assumptions about their identity and about the organs they have, and be able to provide appropriate care based on the person's presentation. As such, we have designed this standard to support affirming social interactions, clarify administrative use cases, and specify important standards developments that enable person-centred care. There are five parts to this Standard and Guide and the framework that underlies it (see Figure 1):

- Part One describes demographic data elements that are common to social, administrative, and clinical domains including Name Used, Personal Pronouns and Gender Used.
- Part Two of this Standard and Guide covers clinical entries related to gender and sex, which includes Gender Identity, Sex at Birth, and Health Services Gender or Sex Marker where gender and sex are conflated by a single-field system.
- Part Three describes the use of Sex Parameter for Clinical Use.
- Part Four outlines Sexual Orientation.
- Part Five provides options for the documentation of Negative Experiences.

In Figure 2, we provide a conceptual framework and high-level information model for all GSSO data elements contained in this Standard and Guide. It is provided as a reference diagram and a preamble to the following content.

Details about each data element presented in the Standard and Guide are provided in the sections that follow. Value options included as part of the common standard will meet most use cases and can be considered the minimum data standard requirement. Expanded codes are included as additional options to the common standard. Exceptional codes are “Unknown” or “NullFlavor” type codes and are designated as common or exceptional.

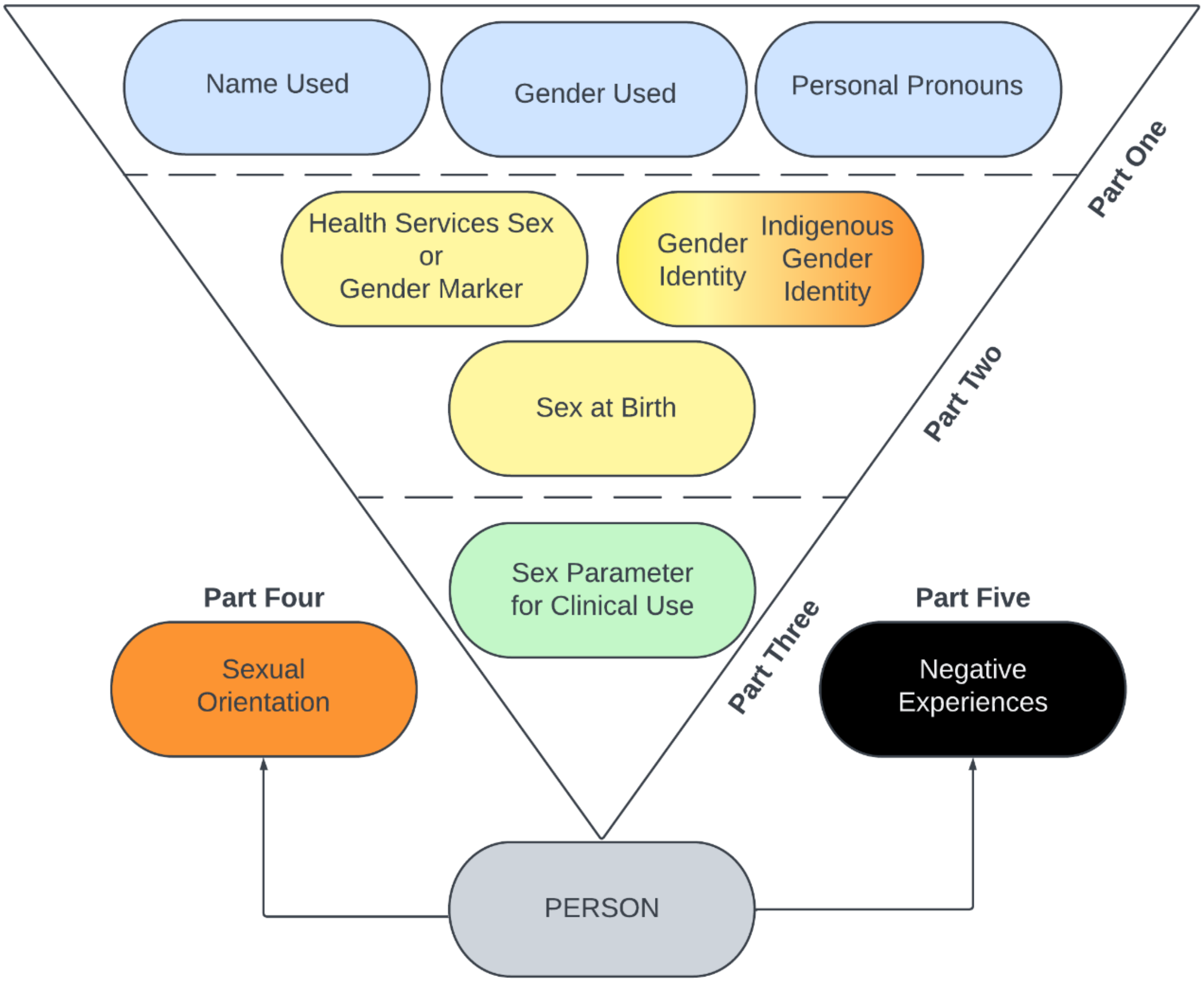

Figure 1: Parts of this Standard and Guide.

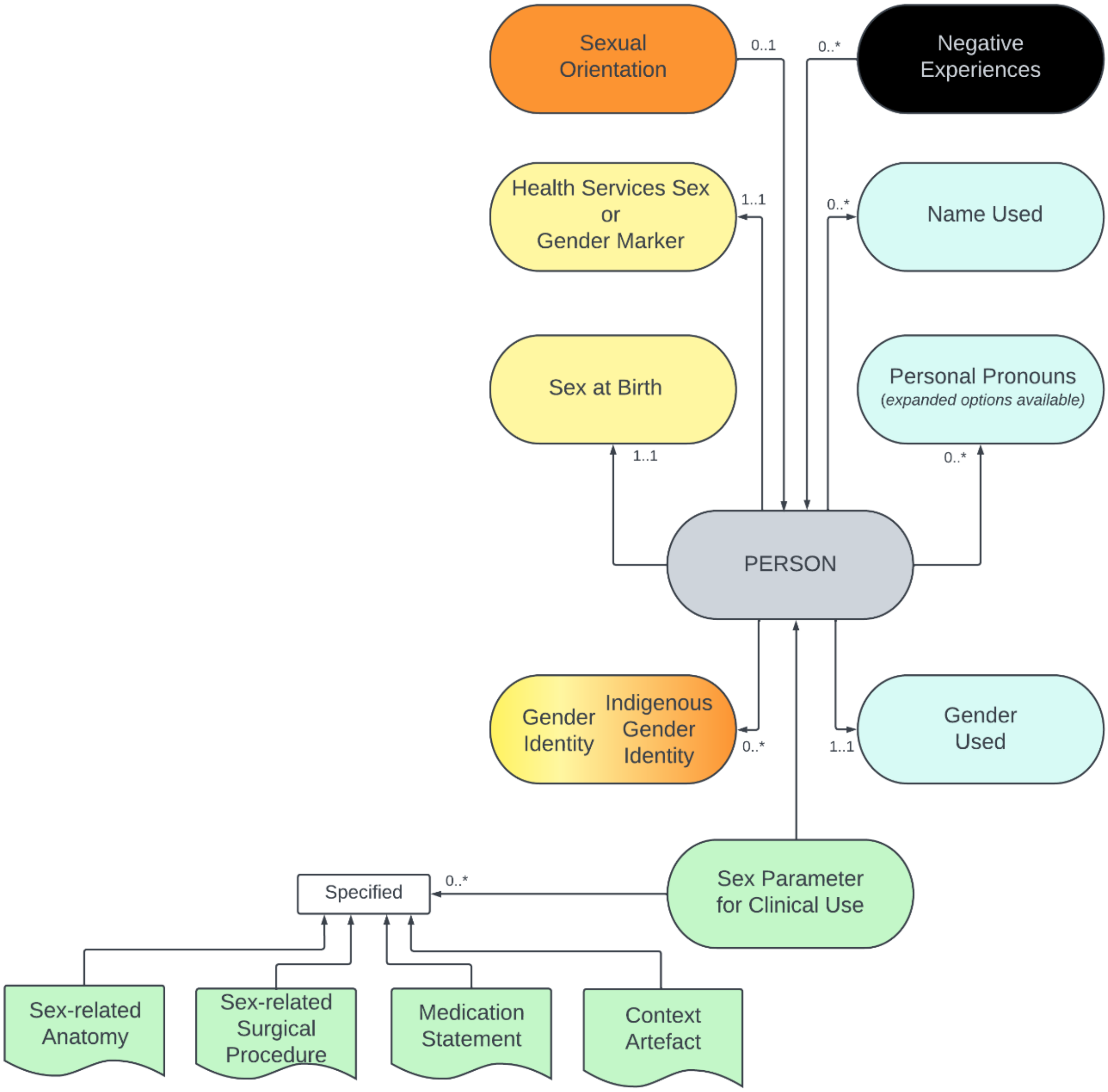

Figure 2: GSSO Conceptual Framework and Information Model.

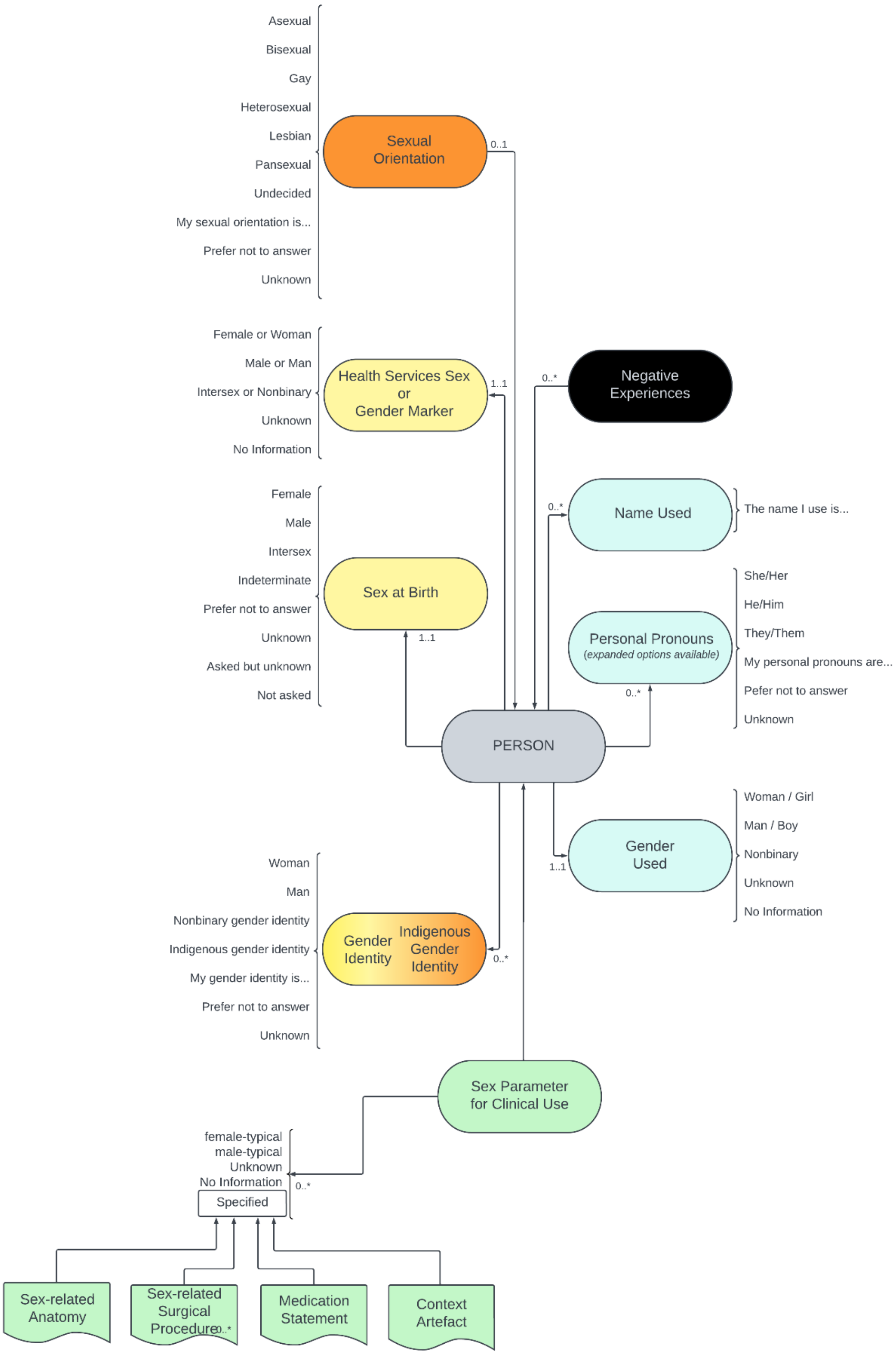

Figure 3: Detailed GSSO Conceptual Framework and Information Model.

6.0 Part One: Demographic Data Elements and Gender Used

Part One of this Standard and Guide outlines the data elements that are common to social, administrative, and clinical domains such as Name Used, Gender Used, and Personal Pronouns. There is some overlap in these concepts with Health Services Sex or Gender Markers and Gender Identity, which will be covered in Part Two. These elements can be implemented and used to support affirming care interactions for all people and are required to support affirming care interactions and can be integrated into EHRs, EMRs, pharmacy and lab information systems, point of service healthcare applications, or wherever they can be used to avoid misgendering, misnaming and outing. These data elements provide the information required for affirming, person-centered interactions and an inclusive healthcare culture.

Details about each data element including scope, usage and interoperability considerations are provided.

6.1. Scope

Part One includes descriptions of demographic data elements common to social, administrative, and clinical domains including Name Used, Personal Pronouns and Gender Used. A conceptual and information model is presented in Figure 4.

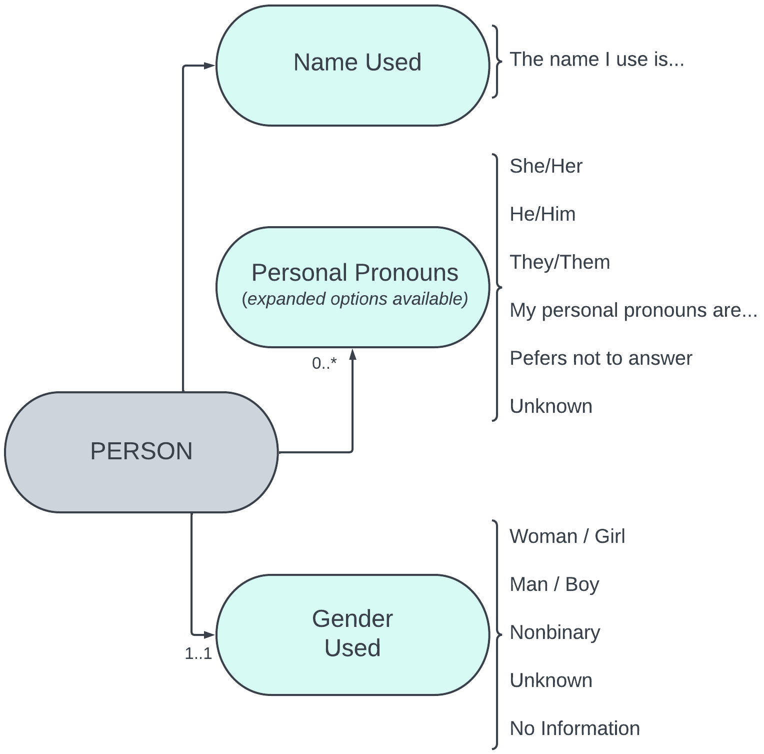

Figure 4: Demographic Data Elements and Gender Used.

6.2. Name Used

People may use different names in different settings. They may use legal names or names other than their legal name to identify themselves. (7) These include nicknames, middle names, language specific alternatives (e.g., Bill, William, Guillaume, Guillermo), or names that affirm gender identity. The BC preferred term for this data element will be “Name Used.”

Name Used is based on the HL7 Gender Harmony Model Data Element Name to Use and aligns with the HL7 Cross Paradigm Implementation Guide: Gender Harmony—Sex and Gender Representation, Edition 1 data element Name to Use. (7,22) This data element is also harmonized with the Canadian Institute for Health Information’s proposed Pan-Canadian Health Data Content Framework Data Content Standard.

Name Used is the name specified by the patient that should be used in context of healthcare and refers to the usual name used by the patient when addressing or referencing them and is obtained when a patient informs you what name they use.

Healthcare service providers should always use the name a patient wishes to go by to reduce potential harm caused by misnaming.(1)

6.2.1. Usage

Digital health systems should support the documentation of the name used by the patient and display it for routine use when the legal name is not required, or in addition to legal names when legal names are required.

When both names must appear (e.g., matching incoming documents to the record), the Name Used should be more visually prominent than the legal name by default. Implementation options include providing the Name Used in parentheses following the person’s legal name in existing banners or headers. Such banners or headers should be provider-facing, and not obfuscated throughout applications to ensure that providers are operating with the correct record for the patient and are aware of their Name Used. (3)

6.2.2. Interoperability Considerations

For Name Used, use patient.Name of datatype HumanName where name.use is “usual.” There may be other contexts beyond patient.Name where a SNOMED or LOINC codes are appropriate, but appropriate SNOMED CT CA and LOINC codes for this element do not yet exist.

6.3. Personal Pronouns

Personal pronouns are linguistic tools used to refer to people instead of using their name, a noun or noun phrase. Gender pronouns are third-person pronouns that may reference a person's gender identity (e.g., he, she, they), and which may be a part of their gender expression. People may use:

- Gender pronouns such as he/him/his and she/her/hers;
- Multiple or mixed pronouns depending on context (e.g., he/they and she/her/they/them);
- Different pronouns in different settings for distinct reasons (e.g., to maintain personal safety);
- Neopronouns such as xe/hir; or
- No pronouns at all (e.g., use name only and without pronouns when referring to a person in the third person).

Healthcare service providers should confirm with the person which pronouns they use. In some instances, misgendering and outing can happen when a person is referred to by pronouns they don't use. In other instances, a person may have strategically asked for you to use pronouns they actually don't use, but only in certain situations in order to keep themselves safe.

6.3.1. Usage

Pronouns must be identified by the patients, and not be assigned by healthcare workers. A person's gender identity or sex does not determine the pronouns that should be used. Individuals should be asked to clearly identify the pronouns to be used in the clinical setting. It is acceptable to use "they/them" pronouns for social interactions if the pronouns of the patient or person are unknown, until such time as they are known. Gender pronouns support affirming care for all people.

Pronouns provided by patients are not optional and therefore should not be referred to as "preferred pronouns".

6.3.2. Interoperability Considerations

The code system for the gender pronoun element is LOINC and the code is 90778-2 Personal pronouns—Reported. Value options are marked as either common or expanded.

The minimum recommended common set of options, which should meet the needs of patients and clinicians in most health organizations, is presented in Table 6.3.2.1. This list of common pronouns aligns with the HL7 Cross Paradigm Implementation Guide: Gender Harmony—Sex and Gender Representation, Edition 1 data element Pronouns (7,22) and is harmonized with the proposed Pan-Canadian Health Data Content Framework Data Content Standard.

Expanded options, which include an expanded array of pronouns that may be useful in specialty services, are also presented. These tables are based on the LOINC answer list for patient-reported personal pronouns.

Exceptional options are presented in Table 6.3.2.2.

The PersonalPronounsConceptCode subset includes common, expanded and exceptional options is available for consumption on the Terminology Gateway.

Table 6.3.2.1 – Common and Expanded Options for Personal Pronouns

Display	Concept	Standard	Code System	Answer ID
he/him	he/him/his/his/himself	Common	LOINC	LA29518-0
she/her	she/her/her/hers/herself	Common	LOINC	LA29519-8
they/them	they/them/their/theirs/themselves	Common	LOINC	LA29520-6
ze/zir	*ze/zir/zir/zirs/zirself*	*Expanded*	*LOINC*	*LA29523-0*
xie/hir	*xie/hir ("here")/hir/hirs/hirself*	*Expanded*	*LOINC*	*LA29521-4*
co/co	*co/co/cos/cos/coself*	*Expanded*	*LOINC*	*LA29515-6*
en/en	*en/en/ens/ens/enself*	*Expanded*	*LOINC*	*LA29516-4*
ey/em	*ey/em/eir/eirs/emself*	*Expanded*	*LOINC*	*LA29517-2*
yo/yo	*yo/yo/yos/yos/yoself*	*Expanded*	*LOINC*	*LA29522-2*
ve/vis	*ve/vis/ver/ver/verself*	*Expanded*	*LOINC*	*LA29524-8*

Source(s): LOINC Personal Pronouns; HL7 Gender Harmony Cross-Paradigm Implementation Guide; CIHI Pan-Canadian Health Data Content Framework

Table 6.3.2.2 – Exceptional Options for Personal Pronouns

Display	Code	Description	Concept	Standard
My pronouns are…	UNC	Free text option[5]	un-encoded	Common
Asked but declined	asked-declined	Prefer not to answer	Asked But Declined	Common
Unknown	UNK	Known to be unknown	unknown	Common
No Information	*NI*	*Value is missing and no reason as to why*	*NoInformation*	*Expanded*
Not asked	*NASK*	*Not sought*	*Not asked*	*Expanded*
Asked but unknown	*ASKU*	*Sought not found*	*asked but unknown*	*Expanded*

Source(s): http://terminology.hl7.org/ValueSet/v3-NullFlavor; https://hl7.org/fhir/R4/codesystem-data-absent-reason.html

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[5] If patient does not use pronouns, may prompt user to enter “use Name Used”.

6.4. Gender Used (Administrative Gender)

Gender Used, previously called Administrative Gender in this standard, represents the gender a person wishes to have recorded on legal documents or for interactions with official agencies (e.g., Drivers' License). Gender Used can be determined by asking "What gender do you want on your documentation?"

It may be helpful to remind the reader here that Gender Used, Gender Identity, and gender expression are separate but related concepts. Gender expression refers to how a person publicly presents their gender (feminine, masculine, gender-neutral) whereas Gender Used is the gender identity they wish to have presented on their legal documentation or recorded in agency databases. Gender Used may be different than the clinical Gender Identity value they wish clinicians to use for affirming care interactions and communication.

6.4.1. Usage

Administrative Gender (now called Gender Used in this standard) is a longstanding data element that conflates sex and gender and should be used in conjunction with the clinical data element Gender Identity to ensure person-centred clinical interactions in multi-field systems.

Since Gender Used may be different than the gender identity of some people, separate data elements with distinct use cases are necessary.

This separation allows for access control to the information in the usual fashion applied in clinical records.

> Gender Used is intended to give people the option to choose the gender entered in government databases that have both a sex and a gender field (two-field systems) and should not be confused with Gender Identity for affirming communication or HSSGM (for single-field systems).

6.4.2. Interoperability Considerations

The code system for Gender Used element is HL7 Administrative Gender with “Other” replaced with a nonbinary gender representation option. “No Information” has been added to the common standard for this data element to accommodate the use case where there is no information for Gender Used available.

The minimum recommended common set of options, which should meet the needs of patients and clinicians in most health organizations, is presented in Table 6.4.2.1. Value options and definitions align with Pan-Canadian Health Data Content Framework and supports a nonbinary use case option for jurisdictions like BC where “X” is an option for citizens to use on their government documentation.

Value options for this data element should be restricted to those presented in Table 6.4.2.1 and should meet the needs of the vast majority of patients and the requirements of most systems.

The GenderUsedConceptCode subset includes common, expanded and exceptional options and is available for consumption on the Terminology Gateway.

Table 6.4.2.1 – Common Standard for Gender Used (Administrative Gender)

Display	Marker	Definition	Code System	Code
Woman / Girl	W or F	Persons who report their Gender Used as a woman or girl. Usage note: corresponds to the administrative gender markers "W" or "F". The “F” marker is required to accommodate legacy system integration. Systems that consume "F" should beware of source definition and provenance.	HL7	Female
Man / Boy	M	Persons who report their Gender Used as a man or boy. Usage note: corresponds to the administrative gender marker 'M'.	HL7	Male
Nonbinary	X	Persons who report their Gender Used as neither exclusively woman, girl, female nor man, boy, male or who do not identify with the binary gender construct.	SNOMED CT CA	33791000087105 |Identifies as nonbinary gender (finding)|
Unknown	U	Persons whose administrative gender is not known at the time of data collection. Unknown corresponds to the administrative gender marker 'U'.	HL7	unknown
No Information	NI	The reason for the value being absent is not known.	HL7	NoInformation

Source(s): [CIHI Pan-Canadian Health Data Content Framework; http://terminology.hl7.org/ValueSet/v3-NullFlavor](http://terminology.hl7.org/ValueSet/v3-NullFlavor)

7.0 Part Two: Clinical Entries Related to Gender and Sex

Gender Identity must be reported by the patient and not assigned by a healthcare provider, staff person, or researcher.(7)

Part Two of this Standard and Guide is intended for use by individuals and organizations that capture clinical data related to Gender Identity and Sex at Birth. These data elements are frequently integrated into EHRs, EMRs, pharmacy and lab information systems, and point of service healthcare applications. Details about each data element including scope, usage and interoperability considerations are provided. For systems where there is only one field to enter sex or gender, this standard describes the use of a field intended to record sex **or** gender data as a Health Services Gender or Sex Marker.

7.1. Scope

Data elements that are in scope for this section are Gender Identity, Gender Expression, Sex at Birth, and a field for recorded sex or gender data where sex and gender are conflated by a single-field system.

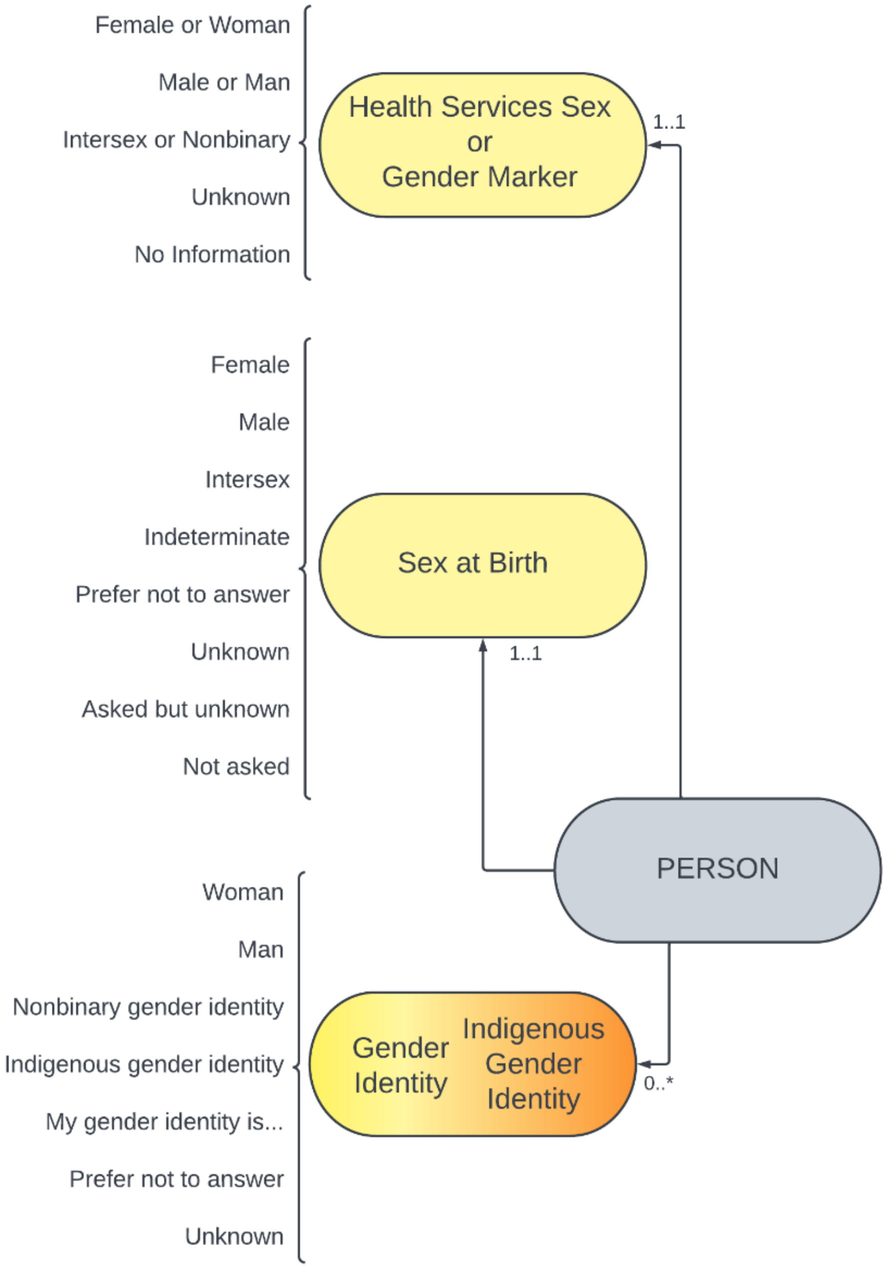

Figure 5: Gender Identity, Gender Expression and Sex at Birth.

7.2. Gender Identity

The data element Gender Identity represents the gender identity that a person identifies with and can determined by asking them:

- “What is your gender identity?” or,
- “What is your gender?”

Gender Identity is an individual’s personal experience of being a woman, man, nonbinary or how the person prefers to self-describe. People may identify with more than one gender identity, or use different gender identities in different settings.(7)

A person's current gender identity may align or differ from what is commonly assumed based on the Sex at Birth (e.g., female, male) or by what indicated on their current legal documents. People who Identify as Indigenous may also identify with Indigenous Gender Identities which include Two-Spirit and Indigiqueer. These identities are by and for Indigenous Peoples and it is inappropriate for non-Indigenous People to use Indigenous Gender Identities.

Gender Identity is intended to support affirming care interactions between clinicians and patients and may or may not be aligned with demographic or administrative data elements such as Health Services Gender or Sex Marker or Gender Used.

7.2.1. Gender Expression

Gender identity and gender expression are separate concepts. Gender expression refers to a person’s behaviour, mannerisms, interests, and appearance, which can be classified as feminine, masculine, gender-neutral, androgynous, etc. A person’s gender expression may or may not align with their gender identity. Gender expression may change over time, independently from or in alignment with a person’s gender identity. Gender expression cannot be deduced from a person’s sex at birth, the gender/sex indicated on their legal documents, or their reported gender identity or pronouns. Gender conformity can refer to someone whose gender identity and expression do align (i.e., a feminine woman) and gender nonconformity can refer to someone whose gender identity and expression do not align (i.e., a masculine woman). Gender expression, including whether someone is gender non/conforming, may nevertheless be important in the context of a clinical encounter. (1)

7.2.2. Usage

Since the data in the Gender Identity element **may be different** than the gender collected in demographics (Gender Used), a separate data element for DHIS is necessary, and should be situated with other clinical data. This separation allows for control of access to the information applied in clinical records.

7.2.3. Interoperability Considerations

The code system for Gender Identity element is LOINC and the code is 76691-5 Gender Identity. The minimum recommended common set of options, which should meet the needs of patients and clinicians in most health organizations in BC, is presented in Table 7.2.3.1. This list of gender identities aligns with the HL7 Cross Paradigm Implementation Guide: Gender Harmony—Sex and Gender Representation, Edition 1 data element Gender Identity(7,22) and is harmonized with the proposed Pan-Canadian Health Data Content Framework Data Content Standard, but can be expanded significantly to meet clinical needs. Expanded options include a wider array of specific gender identities that may be useful in specialty services because they may contain additional detail and are more granular than the common options and are presented in Table 7.2.3.3. It is important to note that we have created Canadian preferred descriptions for many of these SNOMED CT concepts that should be used as the display term in DHIS including woman, man and nonbinary.

The values in this list include gender identities that apply specifically to Indigenous Peoples who identify with them and are not appropriate for use by non-Indigenous people. Common non-Indigenous and Indigenous gender identity value options are presented in presented in Tables 7.2.3.1 and 7.2.3.2 respectively. Expanded options are 7.2.3.3 and 7.2.3.4.

Exceptional options for both Indigenous and non-Indigenous gender identities are presented in Table 7.2.3.5 and include a free text “My gender identity is…” option, an “Unknown” option (null flavor) that can be expanded to “Not yet collected,” “Not asked,” and “Sought not found.” These codes are available from HL7 International and are listed in Table 7.2.3.5

The GenderIdentityConceptCode subset includes Indigenous and non-Indigenous common, expanded and exceptional options is available for consumption on the Terminology Gateway.

Table 7.2.3.1 – Common Options for Gender Identity

Display Term	Fully Specified Name	Code System
Woman/Girl	446141000124107 | Identifies as female gender (finding)	SNOMED CT CA
Man/Boy	446151000124109 | Identifies as male gender (finding)	SNOMED CT CA
Nonbinary gender identity	33791000087105 | Identifies as nonbinary gender (finding)|	SNOMED CT CA

Source(s): LOINC 76691-5 Gender identity; HL7 Gender Harmony Cross-Paradigm Implementation Guide; CIHI Pan-Canadian Health Data Content Framework

Table 7.2.3.2 – Common Options for Indigenous Gender Identity

Display Term	Fully Specified Name	Code System
Indigenous gender identity	33771000087106 | Identifies as Indigenous gender (finding)|	SNOMED CT CA

Table 7.2.3.3 – Expanded Options for Gender Identity

Display Term	Fully Specified Name	Code System
Ciswoman	*51371000087107 | Identifies as cisgender woman (finding)|*	SNOMED CT CA
Transwoman	*51411000087106 | Identifies as transgender woman|*	*SNOMED CT CA*
Cisman	*51361000087103 | Identifies as cisgender man (finding)|*	SNOMED CT CA
Transman	*51401000087109 | Identifies as transgender man (finding)|*	*SNOMED CT CA*
Agender	*51351000087101 | Identifies as agender (finding)|*	*SNOMED CT CA*
Genderfluid	*51381000087109 | Identifies as gender fluid (finding)|*	*SNOMED CT CA*
Transfeminine	*51391000087106 | Identifies as transfeminine gender (finding)|*	*SNOMED CT CA*
Transmasculine	*51421000087103 | Identifies as transmasculine gender (finding)|*	*SNOMED CT CA*

Table 7.2.3.4 – Expanded Options for Indigenous Gender Identity

Display Term	Fully Specified Name	Code System
Two-Spirit	*33801000087109 | Identifies as Two-Spirit gender (finding)|*	*SNOMED CT CA*
Indigiqueer	*51341000087104 | Identifies as Indigiqueer gender (finding)|*	*SNOMED CT CA*

Table 7.2.3.5 – Exceptional Options for Gender Identity and Indigenous Gender Identity

Display	Code	Description	Concept	Standard
My gender identity is…	UNC	Free text option[6]	un-encoded	Common
Asked but declined	asked-declined	Prefer not to answer	Asked But Declined	Common
Unknown	UNK	Known to be unknown	unknown	Common
No Information	*NI*	*Value is missing and no reason as to why*	*NoInformation*	*Expanded*
Not asked	*NASK*	*Not sought*	*Not asked*	*Expanded*
Asked but unknown	*ASKU*	*Sought not found*	*asked but unknown*	*Expanded*

Source(s): http://terminology.hl7.org/ValueSet/v3-NullFlavor; https://hl7.org/fhir/R4/codesystem-data-absent-reason.html

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[6] If patient does not use pronouns, may prompt user to enter “use Name Used”.

7.3. Sex at Birth

Sex at Birth is:

- the sex of a person at birth (i.e., male, female, intersex or indeterminate);
- a clinical finding, usually determined by a clinician based on phenotypic (e.g., genitals or gonads), physiologic (e.g., hormone levels) and/or genetic characteristics; and
- typically recorded shortly after birth by a clinician, and recorded in a clinical information system, legal system and/or document, like a birth certificate or provincial registry.

The concept Intersex is defined as “Persons who are born with any of several variations in sex characteristics, including chromosomes, gonads, sex hormones, or genitals that may not fit typical notions of binary male or female bodies. Intersex people may have characteristics of male and female sexes or may have sex characteristics somewhere along the spectrum between male and female.” Indeterminate is used when the sex characteristics are visually neither male nor female. In either case, further assessment may be required for sex determination and should be updated by the provider if a more definitive sex value can be documented.

7.3.1. Usage

The Sex at Birth finding is frequently used to support clinical care (e.g., interpreting Imaging studies or laboratory tests that refer to binary reference ranges or categories). It is recommended that the storage of this information be masked, or access to it restricted to only those collecting the information to support clinical care and clinicians providing direct patient care. Deidentified Sex at Birth data can also be used for aggregation and reporting.

7.3.2. Interoperability Considerations

In the collection of sex information findings for demographic and administrative purposes or that identified directly by the patient, the code system for the element is SNOMED CT CA.

This data element aligns with the proposed Pan-Canadian Health Data Content Framework Data Content Standard.

The concepts “Intersex” and “Indeterminate” may be represented using the same code ‘I’ in some systems. This is problematic, since the two concepts are not synonymous and have different use cases.

The SexAtBirthConceptCode subset is available for consumption on the Terminology Gateway.

Table 7.3.2.1 – Standard for Sex at Birth

Display Term	Code	Code System
Female	248152002 | Female (finding)	SNOMED CT CA
Male	248153007 | Male (finding)	SNOMED CT CA
Intersex	32570691000036108 | Intersex (finding)	SNOMED CT CA
Indeterminate	32570681000036106 | Indeterminate sex (finding)	SNOMED CT CA

Source: Proposed CIHI Pan-Canadian Health Data Content Framework Data Content Standard

Table 7.3.2.2 – Exceptional Options for Sex at Birth

Display	Code	Description	Concept	Standard
Asked but declined	asked-declined	Prefer not to answer	Asked But Declined	Common
Unknown	UNK	Known to be unknown	unknown	Common
No Information	NI	Value is missing and no reason as to why	NoInformation	Common
Not asked	NASK	Not sought	Not asked	Common
Asked but unknown	ASKU	Sought not found	asked but unknown	Common

Source(s): http://terminology.hl7.org/ValueSet/v3-NullFlavor; https://hl7.org/fhir/R4/codesystem-data-absent-reason.html

7.4. Health Services Sex or Gender Marker

Health Services Sex or Gender Marker (HSSGM) refers to the documented gender or sex of an individual used for clinical, official, or legal purposes **where only one data field for sex and gender is available**, and where it is the value found in the local system and/or historical documentation. This data element may also be called "Administrative Gender or Sex," "Legal Gender or Sex," "Recorded Gender or Sex," "Documented Gender or Sex."

Health Services Sex or Gender Marker is designed for HIS in BC that are not capable of distinguishing between gender and sex.

7.4.1. Usage

For incoming data, provenance of the data including source jurisdiction or organization, purpose (e.g., birth certificate, passport, BC services card), validity period source field name, source field description, and acquisition date, is extremely important for interpreting the content of the data. The local system is just one source of potentially many, each of which represents the actual value found official or legal documents.

The codes for HSSGM should be restricted to the markers presented in Table 7.4.2.1 (M, F, X and U). The X marker can be used by people who do not identify as solely male or female. The U marker can be used by people who do not want a specific gender marker to be visible on their identification. If HSSGM is not required in the local system, default to collecting Gender Used and Gender Identity in the manner described in previous sections.

7.4.2. Interoperability Considerations

The LOINC code 99502-7 Recorded Sex or Gender may be used to support HSSGM. However, incoming data coded as Gender Used should not be automatically used to update Gender, Gender Identity and Sex at Birth fields in DHIS. Given that there may be many instances of this data collected in different contexts, DHIS must be able to consume one too many values from other systems. When reconciling and consuming incoming information, it is important to carefully consider the provenance information before using the sex or gender information to update gender and/or sex fields in the local system.

This data element aligns with the HL7 Cross Paradigm Implementation Guide: Gender Harmony—Sex and Gender Representation, Edition 1 data element Recorded Sex or Gender (7,22) and is harmonized with the proposed Pan-Canadian Health Data Content Framework Data Content Standard data element Recorded Sex or Gender.

The HealthServicesSexOrGenderMarkerConceptCode subset is available for consumption on the Terminology Gateway.

Table 7.4.2.1 – Standard for Health Services Sex or Gender Marker

Display	Marker	Definition	Code System	Code
Female or Woman	F	A value which corresponds to female or female gender (i.e., woman/girl) has been recorded in some context.	LOINC	LA13504-8
Male or Man	M	A value which corresponds to male or male gender (i.e., man/boy) has been recorded in some context.	LOINC	LA15170-6
Intersex or Nonbinary	X	A value which corresponds to 'X' (i.e., nonbinary, intersex, or difference in sex development, etc.) has been recorded or the value is unspecified.	LOINC	LA32969-0
Unknown	U	Known to be unknown.	HL7	UNK
No Information	NI	Value is missing and no reason as to why.	HL7	NI

Source(s): LOINC Recorded Sex or Gender; https://terminology.hl7.org/5.5.0/ValueSet-v3-NullFlavor.html

8.0 Part Three: Sex Parameter for Clinical Use

This section introduces the Sex Parameter for Clinical Use (SPCU) data element which can be integrated with DHIS (e.g., electronic medical record, clinical information systems, pharmacy management systems), and other related health sector POS applications.

It is expected that most clinical and business needs with respect to gender, and sex will be met by the data elements that support affirming communication such as Name Used and Personal Pronouns.

However, in some circumstances, additional parameters and context may be necessary to support person-centered care. SPCU is a parameter that provides guidance on how a recipient should apply settings or reference ranges that are derived from observable information, such as an organ inventory, recent hormone lab tests, genetic testing, menstrual status or obstetric history. SPCU is intended to support safe clinical decision-making. SPCU is a novel design attribute that allows clinicians to communicate additional context about clinical observations and interventions tailored to specific circumstances.

8.1. Scope

There are various methods that can be used to organize or locate sex-related information relevant to care. Sex Parameter for Clinical Use is context-sensitive and may be related to such entries as:

- Sex-related anatomy
- Sex-related surgical procedure
- Medication statement

All sex-related surgical procedures should be found in past procedure lists. Past and current sex-related medications should be found in orders (prescriptions) and lists of medication statements (e.g., best possible medication histories or a collection of continuous, long-term medications maintained by providers and utilized for prescribing).

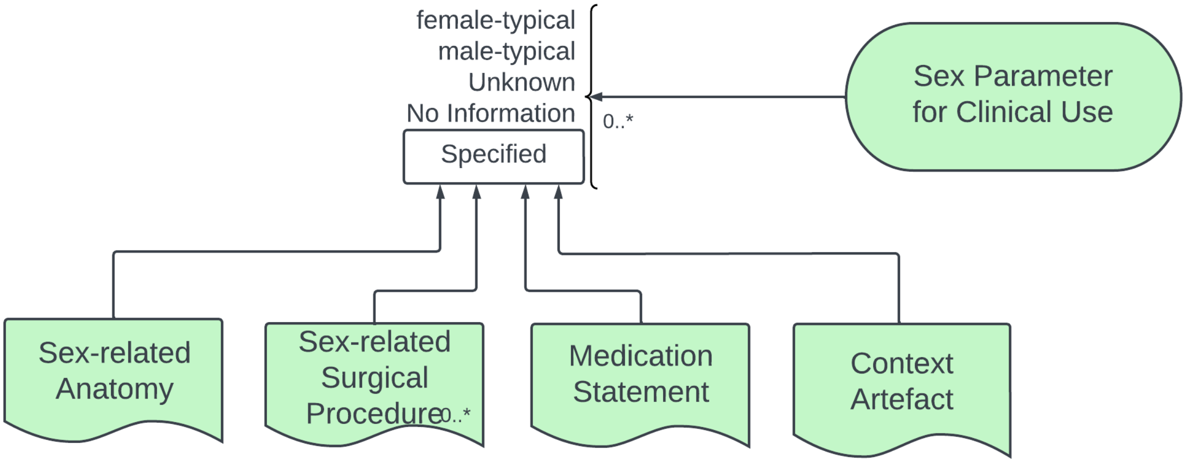

Figure 6: Conceptual and Information Model for Sex Parameter for Clinical Use.

8.2. Sex Parameter for Clinical Use Terms

The following terms should be used where needed to provide the biological distinction of male or female in the context of a healthcare procedure or process.

Table 8.2.1 – Common Standard for Sex Parameter for Clinical Use

Code	Display	Definition	Code System
female-typical	Apply female-typical setting or reference range	Available data indicates that diagnostics, analytics, and treatments should consider best practices associated with female reference populations.	HL7
male-typical	Apply male-typical setting or reference range	Available data indicates that diagnostics, analytics, and treatments should consider best practices associated with male reference populations.	HL7
Specified	Apply specified setting or reference range	Available data indicates that diagnostics, analytics, and treatment best practices may be undefined or not aligned with sex-derived reference populations. Additional information may be available in the form of comments and/or observations.	HL7
Unknown	Unknown	The value is expected to exist but is not known	HL7
NoInformation	No Information	Value is missing and no reason as to why	HL7

Source(s): HL7 Patient Sex Parameter for Clinical Use; http://terminology.hl7.org/ValueSet/v3-NullFlavor

8.3. Usage

Observations related to clinical sex or the patient's anatomy in general are frequently scattered as unstructured text in event compositions such as progress notes or consult reports which does not lend itself to a summative view or clinical decision support. This problem exists for a variety of use cases beyond SPCU, especially when the observation has neither previously or currently represented a health concern in the problem list (e.g., presence of a small non-functioning third kidney, incidental finding of lung atresia or acquired absence of a uterus).

Most of the time, SPCU will be equivalent to Sex at Birth. However, there are important situations where Sex at Birth may not correctly represent the patient's sex for healthcare purposes, and where providers may need specific additional context to provide safe and affirming care. (7)

The absence or presence of certain hormones may impact many physiological markers thereby affecting the interpretation of laboratory results and dosing of some medications.

The presence or absence of certain organs may change the safe configuration for setting up lead vests and positioning for medical imaging procedures.

SPCU was designed to enable clinicians to specify parameters to support decision making and interpretation for clinical orders. It does this by alerting clinicians and technicians to refer to a specific artefact or clinical parameter such as sex-related anatomy, a sex-related medication or hormonal inventory, a surgical inventory, or other useful artefacts. Standardization of context artefacts to support SPCU is currently underway by [HL7 International.](#) Until such context artefacts are available, free text can be used to provide the desired context.

Although this data element still contains a typical male/female sex binary, it is a key step in the evolution of informatics in that it enables the user to avoid making assumptions and refer to refined representations of anatomy, surgery, and medication histories to provide quality care for all people. Once this data element matures, and supporting artefacts are developed, evaluated, and standardized, the male/female binary categorization may become obsolete. When SPCU is relevant (e.g., in a laboratory or medical imaging requisition), this information should be exchanged as a separate field or in a comment at the document or requested item levels. It should not be substituted into Gender Identity, Gender Used, or Sex at Birth fields.

8.4. Interoperability Considerations

Sex related clinical observations used for determination of SPCU can be represented using the HL7 FHIR Observation Resource, qualified with the appropriate clinical codes from LOINC and/or SNOMED CT. Some examples of these are karyotype, phenotype, hormonal values, organ status, surgical procedures, genetic observations, external genital appearance and internal organ morphology.

A summative view representing the patient's "status" could include observations relevant to anatomic status (e.g., presence or absence of organs), physical function/disability, and therapeutic class of selected medications such as sex-related hormones provided historically and currently. Such an approach reduces clutter in the problem list and provides a useful alternative to inappropriate or disrespectful problem list entries such as "Transgender" which is neither a problem nor a health concern. Regardless of how these observations are collected, organized, and displayed, the tables below provide terms and codes to satisfy clinical documentation needs for clinical use.

The minimum recommended common set of options, which should meet the needs of patients and clinicians in most health organizations, is presented in Table 8.2.1. This list of SPCU value options aligns with the HL7 Cross Paradigm Implementation Guide: Gender Harmony—Sex and Gender Representation, Edition 1 data element SPCU(7,22) and is harmonized with the Canadian Institute for Health Information proposed Pan-Canadian Health Data Content Framework Data Content Standard.

8.4.1. Sex Related Anatomic Inventory

Presently, there are several ways in which observations are collected and organized for use in a DHIS. Sex related anatomy data, whether collected and organized as an anatomical inventory or collected as observations over time, can be used to enrich clinical context and build accurate automated decision support within the DHIS. Observations can support appropriate screening or case finding and provide essential context that enables clinicians to provide quality care. Table 8.4.1.1 presents some SNOMED CT concepts to consider for the presence or absence of sex-related anatomic structures can be used to provide additional context via SPCU.

Work to develop and standardize context artefacts to support SPCU, such as anatomical inventories and anatomy subsets, is currently underway by HL7 International.

Table 8.4.1.1 – Sex Related Anatomy Present/Absent– SNOMED CT CA (not exhaustive)

Organ	Concept—Present	Concept—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
Penis	18911002 | Penile structure; qualifier 52101004 | Present	18911002 | Penile structure; qualifier 2667000 | Absent
Prostate	41216001 | Prostatic structure; qualifier 52101004 | Present	41216001 | Prostatic structure; qualifier 2667000 | Absent
Testes	42774007 | Both testes; qualifier 52101004 | Present	237804005 | Absent testes
Uterus	289619002 | Uterus present	248942000 | Uterus absent
Vagina	289511006 | Vagina present	248871003 | Vagina absent

8.4.2. Sex-Related Hormone Medication History

Sex-related drug therapy or surgical procedures may be relevant in referrals or specification of SPCU.

The sex-related hormone medication history allows structured entry to unambiguously describe the needed context.

DHIS medication list should include medications of all types including sex related hormone therapy, 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 an associated drug class such as the World Health Organization (WHO) Anatomic Therapeutic Chemical (ATC) Classification, it is possible to group drugs for viewing or exchange in a document.

Tables 8.4.2.1, 8.4.2.2, and 8.4.2.3 present sex-related hormone concepts, age and duration of first use,

Table 8.4.2.1 – Sex-Related Hormone Medications

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 (puberty suppressants)	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).

Table 8.4.2.2 – Age of First Use and Duration of Use

Concept	Description
Effective period by age	Age started; age ended
Effective period by date	Date started; date ended

Table 8.4.2.3 – Sex-Related Hormone Medication Treatments for Clinical Documentation

Concept	Description
707266006 |Androgen deprivation therapy	Androgen antagonists spironolactone, cyproterone acetate, 5-alpha reductase inhibitors, GnRH agonists and antagonists
243125009 |Estrogen hormone therapy	Hormone therapy with estrogens
243126005 |Progestogen hormone therapy	Hormone therapy with progestins
724163007 |Testosterone replacement therapy	Hormone therapy with testosterones

8.4.3. Sex Related Surgical Procedures

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. A non-exhaustive list of procedures is presented in Table 8.4.3.1 and should be un-coupled from any gender-coded marker:

Table 8.4.3.1 – Sex Related Surgical Procedures

Term	SNOMED CT Procedure Code	Description
Breast construction	172067003 | Breast prosthesis operation 52852000 Insertion of bilateral breast prostheses	Procedure of implantation of prosthesis to enhance the size or change
Chest contouring	33496007 | Reconstruction of breast 836272003 | Gender confirmation top surgery	Procedures to remove breast tissue and create a flatter and/or sculpted chest. This surgery could also include breast reductions.
Facial surgery	62996004 | Reconstruction of facial bones 77419007 | Reduction osteoplasty of facial bones 119863003 | Lip reconstruction 232470004 | Reconstruction of nose	Procedures to make alterations to the facial bones, cheeks, forehead, nose, hairline, and areas surrounding the eyes, ears, or lips.
Feminization Laryngoplasty	173013001 | Chondroplasty of larynx	Procedures to remove the anterior thyroid cartilage, collapsing the diameter of the larynx as well as shortening and tensioning
Gonadectomy, Orchidectomy, Oophorectomy	236334001 | Total orchidectomy 83152002 | Oophorectomy	Procedures to remove the testes or ovaries which results in a loss of gonadal production of sex steroids.
Hysterectomy	236886002 | Hysterectomy 116140006 | Total hysterectomy	Procedure for the removal of the uterus, ovaries, and fallopian tubes.

Term	SNOMED CT Procedure Code	Description
Labiaplasty	276187001 | Operation on labia	Procedure that involves creating or modifying the labia minora (inner lips), and/or the labia majora (outer lips).
Liposuction or lipofilling	302441008 | Liposuction of subcutaneous tissue	Technique that removes or transfers body fat to achieve the desired body contour from specific areas of the body, such as the abdomen, hips, thighs, buttocks, arms, or neck.
Mastectomy	27865001 | Excision of bilateral breasts (procedure)|	Procedure to remove breast tissue that covers the chest muscles.
Metoidioplasty	890194007 | Gender confirmation metoidioplasty	Procedures for clitoral release plus urethral lengthening and incorporation into penis, increased girth of penis using skin from the labia.
Penectomy	80855002 | Amputation of penis	Procedure to remove part or all the penis.
Phalloplasty	890193001 | Gender confirmation phalloplasty	Procedure that creates a penis, scrotal sac, and testes using genital and tissue grafted
Scrotoplasty	120024003 | Scrotum reconstruction	Procedure used to either repair or treat an existing scrotum or to create a scrotum and often paired with testicular implants.
Testicular implants	77171007 | Insertion of testicular prosthesis	Procedure to cosmetically fill a newly created or repaired scrotum

Term	SNOMED CT Procedure Code	Description
Urethroplasty, Urethral lengthening	287762004 | Reconstruction of urethra	Procedure to lengthen the urethra and incorporate it into the penis.
Vaginectomy	65756000 | Vaginectomy	Procedure to remove all or part of the vagina.
Vaginoplasty	176687003 | Vaginoplasty	Procedure that creates a vagina and vulva (including mons, labia, clitoris, and urethral opening). May be combined with Vulvoplasty.
Vulvoplasty	120033001 | Vulva reconstruction	Procedure that creates the vulva (including mons, labia, clitoris,

9.0 Part Four: Sexual Orientation

Sexual orientation refers to how a person describes their sexuality, or as “who a person is romantically or physically attracted to”. Sexual Orientation has dimensions of sexual identity, sexual attraction and sexual behaviour. Authentic disclosure of sexual orientation by a person can be important for quality healthcare, especially in the context of sexual health assessments, and is often an element of clinical interviews. (23) Sexual Orientation is also often used in research and by governments in public health to measure inequities between populations.

Documentation of sexual orientation for clinical purposes with the informed consent of the patient can serve to positively influence outcomes addressing related health concerns.[7] This data element is intended to support a single place for general findings related to sexual orientation and can be used to document findings related to sexual attraction and behaviour that are not presently included in the subset.

The Sexual Orientation data element is harmonized with the Canadian Institute for Health Information’s proposed Pan-Canadian Health Data Content Framework Data Content Standard. Value options for Sexual Orientation which should meet the needs of patients and clinicians in most health organizations is presented in Table 9.0.1.1. Exceptional options are presented in Table 9.0.1.2.

The SexualOrientationConceptCode subset is available for consumption on the Terminology Gateway.

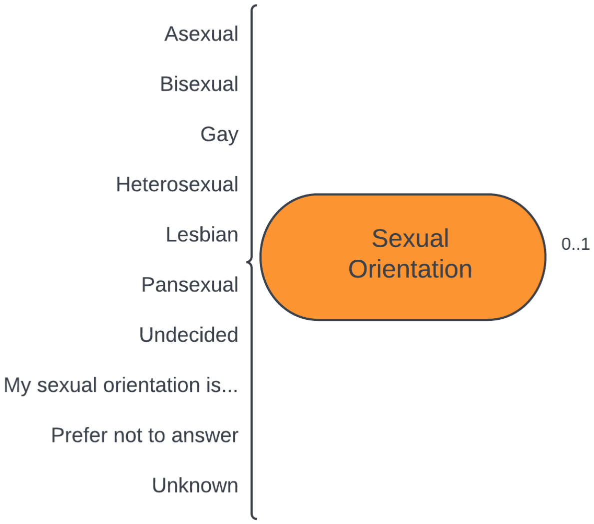

Figure 7: Conceptual and Information Model for Sexual Orientation.

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[7] Maragh-Bass AC. The "Ask" Is the "Answer": Implementing Routine Documentation of Sexual Orientation and Gender Identity in Health Care. Am J Public Health. 2019 Aug;109(8):1071-1073

Table 9.0.1.1 – Common Options for Sexual Orientation

Preferred Term / Display	Code	Code System
Heterosexual	20430005 | Heterosexual (finding)	SNOMED CT CA
Lesbian	89217008 | Female homosexual (finding)	SNOMED CT CA
Gay	38628009 | Homosexual (finding)	SNOMED CT CA
Bisexual	42035005 | Bisexual (finding)	SNOMED CT CA
Asexual	765288000 | Sexually attracted to neither male nor female sex (finding)	SNOMED CT CA
Pansexual	51431000087101 | Pansexual (finding)	SNOMED CT CA
Undecided	1064711000000108 | Undecided about sexual orientation (finding)	SNOMED CT CA

Source(s): Action Plan to Modernize GSSO Information Practices in Canadian EHRs.

Table 9.0.1.2 – Exceptional Options for Sexual Orientation

Display	Code	Description	Concept	Standard
My sexual orientation is…	UNC	Free text option[8]	un-encoded	Common
Asked but declined	asked-declined	Prefer not to answer	Asked But Declined	Common
Unknown	UNK	Known to be unknown	unknown	Common
No Information	*NI*	*Value is missing and no reason as to why*	*NoInformation*	*Expanded*
Not asked	*NASK*	*Not sought*	*Not asked*	*Expanded*
Asked but unknown	*ASKU*	*Sought not found*	*asked but unknown*	*Expanded*

Source(s): http://terminology.hl7.org/ValueSet/v3-NullFlavor; http://terminology.hl7.org/CodeSystem/data-absent-reason

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[8] If patient does not use pronouns, may prompt user to enter “use Name Used”.

10.0 Part Five: Documenting Negative Experiences

Negative experiences such as discrimination are barriers to care and can result in avoidance of healthcare. The underlying principle of this standard is the promotion of health equity by addressing DHIS design that contributes to bias. Fundamentally, we believe that when providers have access to specific information about a person's gender such as their pronouns, their name used, and their gender identity, negative experiences of healthcare related to misnaming, misgendering and accidentally "outing" patients can be avoided, and diverse people can access preventive and affirming care. In this part of that standard, we outline concepts representing negative experiences in healthcare.

When gender expression is considered to play a role in a patients reported negative experiences or worries related to gender, it can be documented as needed in encounter notes with terms such as "feminine," "gender-neutral", "masculine", "gender-conforming" or "gender-nonconforming."

Table 10.0.1 – Coding Negative Experiences

Term	Code	Synonym
Negative experiences related to healthcare system in relationship to gender identity	TBD	• Experiences related to: ○ cisnormative bias in healthcare ○ cisnormativity in healthcare ○ cissexism in healthcare ○ gender-based discrimination in healthcare ○ genderism in healthcare ○ masculonormativity in healthcare ○ misogyny in healthcare ○ sexism in healthcare
Negative experiences online related to gender identity	TBD	• Experiences: ○ gender-identity-related cyber-bullying ○ online abusive behaviour related to gender identity

Term	Code	Synonym
Negative experiences related to gender identity	TBD	• Experiences: ○ binarism ○ cisgenderism ○ cissexism ○ enbyphobia ○ exorsexism ○ genderism ○ genderphobia ○ misandry ○ misogyny ○ sexism ○ transphobia
Finding related to misgendering or deadnaming	TBD	• Finding related to mis-gendering or dead-naming
Worries related to outward visibility of gender identity	TBD	• Worries related to: ○ gender expression ○ gender non-conformity
Worries about being open about gender identity	TBD	• Worries about coming out, gender identity

Term	Code	Synonym
Worries about discrimination related to gender identity	TBD	• Worries about: ○ anti-transgender discrimination ○ binarism ○ cisgenderism ○ cissexism ○ enbyphobia ○ exorsexism ○ gender-based discrimination ○ genderism ○ genderphobia ○ misandry ○ misogyny ○ nonbinaryphobia ○ sexism ○ transphobia

Term	Code	Synonym
Worries about personal safety in relationship to gender identity	TBD	• Worries about experiencing: ○ enbyphobic violence ○ gender phobic violence ○ gendered violence ○ misogynistic violence ○ nonbinary phobic violence ○ transphobic violence
Negative experiences related to healthcare system in relationship to sexual identity	TBD	• Experiences related to: ○ acephobia in healthcare ○ amatonormativity in healthcare ○ aphobia in healthcare ○ arophobia in healthcare ○ biphobia in healthcare ○ heteronormative bias in healthcare ○ homophobia in healthcare ○ lesbophobia in healthcare ○ mononormativity in healthcare ○ sexual-orientation-based discrimination in healthcare

Term	Code	Synonym

Negative experiences related to sexual identity	TBD	- Experiences:
		  ○ acephobia
		  ○ aphobia
		  ○ arophobia
		  ○ biphobia
		  ○ homophobia
		  ○ lesbophobia

Negative experiences online related to sexual identity	TBD	- Experiences online abusive behaviour related to sexual identity

Worries about personal safety in relationship to sexual identity	TBD	- Worries about experiencing:
		  ○ acephobic violence
		  ○ aphobic violence
		  ○ arophobic violence
		  ○ biphobic violence
		  ○ homophobic violence
		  ○ lesbophobic violence

11.0 Implementation Guidance

This Standard and Guide can be implemented in whole or in part, depending on context of use and the design of the DHIS in which it is being implemented. Implementers, which may include vendors, health authorities, primary care clinics, lab systems, pharmacy systems and legacy systems, will all play their part in modernizing BC's healthcare system, and in making it world-class.

Full implementation will require a significant effort to make appropriate changes to digital health information systems.

The purpose of these changes is to allow the digital health information systems to accurately represent the sex, gender, and sexual orientation diversity of persons accessing healthcare in BC.

Affirming care cultures will require implementation of expanded gender identifiers outlined in the Standard and Guide, as well as elements that support affirming care interactions such as Name Used and Pronouns. Making these changes will require doing an inventory and assessment of how DHIS collects data about gender and how that data is presented to users.

11.1. Collection of GSSO Information

The Government of BC government typically collects information about people through written forms (online or paper) or through verbal interaction (face to face or by telephone or in telehealth encounters). This information is then entered into a digital system or recorded on paper.

Both situations require tailoring of the methods of collection of GSSO information to the specific interaction format.

It is recommended that all patients, at a minimum, have fields in their record that represent Gender Used, Gender Identity (if different from Gender Used), Pronouns, and Name Used (if different from the name on insurance or legal documents) that can be viewed by staff accessing the system to provide care. If such fields are unavailable, then consideration should be made to use a comment field.

The following sections provide guidance on how to collect gender information in four mediums: paper, online, telephone/telehealth and in-person.

11.2. Advice for form-based collection of Gender

11.2.1. Considerations for Paper Collection[9]

Collecting any type of data on paper results in increased risks related to data accuracy.

There are two key reasons for this:

- The first risk is that respondents or patients can provide data in inconsistent or difficult-to-interpret ways. These difficulties can range from respondents using a variety of terms (e.g., Male Gender, M, Man, Guy), having illegible handwriting, and notes written in the form's margins.
- The second risk is that data collected on paper forms eventually needs to be digitized. This process can include manual data entry (which also has a risk of input or transcription errors), or scanning, which can result in the data being stored as an image rather than an alphanumeric data type which can be more easily consumed. When possible, online data collection is preferred.

11.2.2. Considerations for Online Collection[10]

Online data collection is preferable to paper collection because data collected via online forms are stored directly in digital systems and are often immediately available to use.

An important consideration for online forms is the requirements for integration with other information systems, which often entails mapping different terms or value options that are similar, but not identical, both textually and semantically.

These terms can be standardized to reference terminology standards such as LOINC and SNOMED CT in online forms. Online forms can also be set up to include skip-logic (also called IF THEN logic) which enables nested data collection (e.g., if question 1 is answered a specific way, then question 2 is applicable) and well as business rules (e.g., no answer equals Unknown).

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[9] Content is taken from the OCIO *Guidelines to the Gender Identity and Sex Information Data Standard*

[10] Ibid

11.3. Advice for the Verbal Collection of Gender, Sex, and Sexual Orientation information (Telehealth or In-person)[11]

Depending on time and other constraints, one benefit of telephone and in-person data collection may be that it presents a good opportunity to build rapport by having respondents report their gender identity using their own words. However, as with paper and online collection, the focus should remain on collecting information that adheres to the Standard and Guide, and then providing opportunities for individuals to provide more nuanced responses.

11.3.1. Considerations for verbal collection[12]

With verbal collection, the respondent may provide a response that does not align with one of the available options, increasing the difficulty associated with interpreting and recording. Unless responses are recorded in a system, this collection method shares a risk with paper collection: the eventual digitization of responses. This process can include manual data entry (which also has a risk of input errors) or scanning (which can result in the data being stored as an image). When possible, recording responses directly into a DHIS is preferred. In some contexts, language translation may also be important.

In telehealth or in-person interactions, if the patient will have an ongoing relationship with the program, ensure all staff are aware of how to ask about identified pronouns with sensitivity and consider whether this information will also be stored as data in any information systems.

Sample Script(s):

- “My name is Lina and I use the pronouns she and her. What pronouns do you use for yourself?”
- “What pronoun, like "he, she, they", would you like me and my colleagues to use when referring to you?”

Please see the section titled “The Importance of Language” for more information.

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[11] Ibid

[12] Ibid

11.4. Advice for the Collection of Gender, Sex, and Sexual Orientation Information[13]

While the common standard presents the most common gender information that can be collected, program and services areas have the option of collecting additional information (expanded options) about gender identity that is more nuanced and detailed than is provided in the common standard. This allows individuals to provide gender information in their own words which can help program areas build rapport with their patients and provide more information about the patients the program serves.

It is recommended that program areas focus on the collection of data in the format presented in the Standard and Guide and then if desired, provide options for individuals to expand concepts in their own words. This is recommended because it is exceedingly difficult to code open-ended responses. Attempting to standardize open-ended responses can negatively influence data quality, accuracy, and coverage. When providing any list of GSSO options to select from, it is important to provide an option for the person not to answer (prefer not to answer) and a free-text option where they can describe their gender identity, personal pronouns or sexual orientation using their own words.

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[13] Ibid

11.4.1. Making Responses Voluntary

It is best practice, when possible, to make demographic responses or responses of a personal nature optional, including questions about gender, sex, or sexual orientation. For example, allowing people to skip over a question or providing a response option like “prefer to not respond.”

- Be aware that voluntary response may impact information quality and completeness of your dataset and any business processes linked to them.
- Gender Used supports identity matching, especially in billing or matching incoming paper or digital records. It also enables gender affirming interactions when there is a disparity between their gender identity and how they wish to be known as in social interactions. With this flexibility, patients are likely to become more trusting of how information will be maintained or used and more likely to provide authentic information.

With surveys, it is especially important to consider the response rates as part of any GBA+ analysis. Helpful questions to consider include:

- How will you respond to questions about how the information will be maintained, used, and/or disclosed?
- Can you collect Gender or Gender Identity information on a voluntary basis (status quo)?
- If gender information is mandatory, what legislation, policy, business process requires it?

11.5. The Two-Step Method

The two-step method is an evidence-based method for collecting Gender Identity and Sex at Birth endorsed by expert organizations such and the Fenway Institute and has been adopted and endorsed by the CIHI in support of health equity-measurement. The adoption of a 2-step method and standardized process to collect one's gender and sex that involves asking all patients the questions:

- "What gender would you like to be identified as?", or "what is your gender"?
- Followed by if clinically relevant, "What was your sex at birth?"

This process helps staff provide gender inclusive care and avoid assumptions about a person's gender and sex that can impact the delivery of clinically competent care.

Patients must have the option to opt out of answering the question.

11.6. Gender, Sex, and Sexual Orientation Display Considerations

When gender information must be displayed for official identification purposes (such as identity cards), the markers “W”, “M”, “X”, or “U” can be used.

- The “F” marker for gender may be necessary to accommodate legacy systems but should be replaced by “W” when possible.
- The gender “X” marker will be available to individuals whose current gender is not exclusively female or male.
- The gender “U” marker will be used to represent the variations of “Unknown” which includes accommodating individuals who prefer not to disclose their gender.

11.7. Business Rules

The following are general business rules that apply to the core gender identity and sex, and sexual orientation components.

- Gender or sex information is both personal and health information and therefore must only be collected as authorized under FOIPPA.
- FOIPPA states that personal information may be collected under Section 26 of the Act, while the use and disclosure of personal information by public bodies is in accordance with Sections 32 and 33.
- Ministries, agencies, Health Authority boards and commissions must have administrative controls in place to ensure that they collect the minimum amount of personal information necessary for the purpose, and that the information is directly related to an operating program, clinical service, or activity (e.g., clinical decision support, gender-based analysis, program and service delivery, research, operational decisions).
- Gender and Sex are two distinct concepts and should not be used interchangeably. Gender is comprised of Gender Used and Gender Identity.
- Gender Used should be collected routinely and displayed by default where gender information is needed for identity matching, or where a patient-specified Gender Identity has not been recorded. In cases where Gender Identity is shared with clinicians and consent to record and share with the care team is granted, Gender Identity should be displayed to support gender affirming clinical interactions.
- Gender Identity should be identified by the patient and should not be assumed or assigned by a healthcare provider, staff member, or researcher based on their Sex at Birth (e.g., if sex hormones need to be known as part of medical information this should be asked separately rather than inferred by a person’s gender).
- Sex at Birth should only be displayed and used for clinical purposes and may be collected in lieu of, or in addition to gender in a separate field.
- Sex information will be collected and used by exception for those health programs or services where biological information is necessary (e.g., medical, clinical, population health, and research purposes).
- Sex at Birth and/or Sex Parameter for Clinical Use in correspondingly named fields, should be used for all relevant lab and imaging requisitions.

  - Note: A clear distinction between gender, Sex at Birth, and Sex Parameter for Clinical Use must be made for patient safety purposes.

- Sex Parameter for Clinical Use should only be documented when clinically required and in a manner or location that will alert only those who need the information. Free text can be used to provide context until such time as standard context artefacts are available.

- It is important to note that characteristics influencing sex assignment include chromosomes, gonads, sex hormones (e.g., testosterone or 17α-hydroxyprogesterone levels), and genitals. Final determination may be based on any number of such characteristics.

- For some health programs and services, the “X” marker can be used by people who do not want a specific gender identity or sex marker to be visible on their identification. Individuals with the “X” marker must be treated with respect and mindfulness of their choice to ensure appropriate use of their name and pronouns.

- Sexual Orientation documentation should be maintained in the clinical documentation domain, with appropriate access controls.

11.8. Advice for Indirect Collection of Gender Information

11.8.1. When can a guardian of a minor provide the gender information of the minor?[14]

A guardian may act for a minor if the minor is incapable of providing their own information, but only if it is within the scope of the guardian's duties or powers.

As a best practice, when possible, ask the minor directly. This will be particularly important when providing programs or services to teenagers with whom you are building trust and rapport.

11.8.2. When can a representative of an adult provide the gender information of the adult?[15]

A representative of an adult may provide the adult's gender information in circumstances where a person may be unable to answer the question asked (e.g., in the case of death, or incapacity because of disability, injury, sickness, or absentia) and, only if the power to provide gender information is within the scope of the representative's duties or powers.

In both these situations, it is important to try to balance gender affirmation, consent to disclose, and legal guardians' or representatives' information needs.

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[14] Ibid

[15] Ibid

11.9. Understand Your Systems

Systems may be enterprise systems (e.g., databases, LAN drives, SharePoint, EDRMS, intranet, internet) or line of business Information Management/Information Technology IM/IT systems (e.g., databases, case management systems, cloud-based systems). In either case, the following steps may be helpful:

- Identify the official that is the system owner or is responsible for managing each system (i.e., system administrator/architect/developer) and who is responsible for managing the information in the system (i.e., head of the work unit/program area/information owner/data custodian).
- Perform an inventory of the data held by your systems.
- Identify which of your systems are used to collect and store gender and sex information within your business area.
- Create and implement a plan to upgrade this information to adhere to this Standard and Guide.
- Give higher priority to systems where data is relied upon heavily by the program area or shared widely with other program areas or agencies.

11.10. Understand the Information in Your Systems

When the gender information that is collected by your systems is identified, answer the following questions about the information contained within your systems:

- Under what context was the information collected?
- How was the information collected (e.g., directly from the individual, or indirectly from sources other than the individual the information is about)?
- Who entered the information (e.g., government employee, clinician, the individual the information is about)?
- Are there any quality issues with information (e.g., incomplete data field that conflates sex and gender)?
- Are there any biases present in the information collection (e.g., collection makes assumptions about the sex or gender of individuals based upon appearance or outdated information)?
- What other sources may be used to understand the nature of the information within systems (e.g., Personal Information Registries, Privacy Impact Assessments, Security Threat and Risk Assessments, and internal information management documentation)?

11.11. Compare How Your Information is Collected, Used and Stored to the Standard's Recommendations

Identify:	
Which parts of your information technology systems are already adherent to the standard?	
What information required by the Standard and Guide is not being captured?	
How can additional or different information be collected to meet the standard (e.g., maintenance of long-term medication lists, structured documentation of surgical procedures, documentation of Pronouns or Name Used)?	• This would be expected to have far-reaching benefits.
Whether or not any of the non-compliant information can be re-coded or transformed to meet the Standard and Guide?	• The existing data in a local system may have ambiguous sex and gender information if there has been only one field to represent sex and gender. ○ Getting to accurate sex and gender information may require considerable process re-design and staff training after the digital health information system has been updated to support the required data elements.

Identify:	
	• A two-pronged approach may be helpful: ○ Validation of gender at encounters through the approach described earlier in this guide can be done. ▪ A demographic “reviewed” flag with data (e.g., like clinical reviews of allergies, problem list) would likely make this more efficient. ○ Utilize other information in the digital record as well as clinical knowledge of the patients to target records for review (e.g., use of hormonal therapy and history of specific surgeries). ▪ In the clinical setting, Sex at Birth and Sex Parameter for Clinical Use can be particularly important in some circumstances (e.g., laboratory requisitions for tests where reference range is influenced by clinic sex).

Identify:	
	• Ongoing incoming data may inform legitimate updates to existing sex or gender information, but they may also be ambiguous or erroneous/out of date. ○ When the sending system has mixed gender and sex information in the same field, it should be sent with contextual information so the recipient can choose whether to update the Gender field. ○ The document/result matching process in digital health information systems should allow the user to reconcile gender, sex, and other information when matching is uncertain.

11.12. Map the Design of the Information Elements

- Develop a schema or table to describe both the standard data elements and any additional gender information that needs to be captured (e.g., free form fields).
  - This could be in the form of a Data Dictionary (e.g., PDF, Document, Table, JSON Schema).
- Ensure there is metadata to support all the data elements that are captured.
- Design the data and system with interoperability in mind so that information can easily be shared and used by others.
- Consider how easily the data in the system can be extracted and shared with others.

12.0 Changing Gender Information

Consistent with our aim of enabling the BC government's collection and maintenance of accurate data about an individual's gender identity, individuals have the right to apply to change how they are identified by BC government programs and documents. Please consider the following advice when assisting individuals with changing their gender information to ensure that the individuals can maintain identity documents and personal records that align with their gender identity while also supporting the integrity of government programs.

> *"The BC provincial government is working to standardize how gender identity is recognized across all provincial programs and services.*
>
> *However, some programs currently require either an M or F.*
>
> *Would you be okay advising me of which option you would feel most comfortable selecting at this time?*
>
> *Alternatively, you can always think about it and reach out to us later."*

The amount of documentation required to change an individual's gender information should be proportionate to the degree to which gender information determines how an organization interacts with an individual. For example, changing gender information in medical records or government identification would require more documentation from an applicant than changing gender information that is collected from an individual voluntarily for the purpose of an organization's GBA+ analysis.

<u>Sites for Changing Information</u>:

- BC Services Card: Change Your Name, Address or Gender: Changing/Correcting a Name, Birthdate, or Gender - Province of British Columbia (gov.bc.ca)
- Vital Statistics: Change Gender Designation on BC Birth Certificates: https://www2.gov.bc.ca/gov/content/life-events/birth-adoption/births/birth-certificates/change-of-gender-designation-on-birth-certificates

Key Points to consider when assisting someone who is changing their gender information:

- Let the person know that you are there to help them get what they need.
- When dealing with programs that have not yet implemented X or W, as a gender identifier, explain that the work is ongoing. If someone needs help, we recommend that they contact the Ministry or Health Authority in their area. For example, by saying citizens can be directed to government websites to assist them in changing their sex or gender information on their Birth Certificate, BC Services Card, BC Driver's License or BC ID.

Non-intrusive requirements for changing gender information:

a) Statutory declaration by the individual or, in certain situations, a third-party attestation supporting the application should be considered sufficient to change sex or gender information.

b) During the time it takes to process a change request and upon request, use the new name and gender title for all purposes (e.g., emails, phone directories, corporate identification/access cards, name plates).

Gender and sex documentation can change over time, so it is important to:

a) Understand how this can impact administrative data, longitudinal studies, and the overall integration of data.

b) Have a clear understanding of which other public bodies are notified when an individual makes changes to their gender.

c) Prioritize updating systems that are currently in use or are likely to be used in the future (for those government organizations that must change multiple and separate IT to accommodate a change in gender information, prioritize changing systems that are currently in use or are likely to be used in the future).

d) Keep an annotated record when gender information is changed.

13.0 Resources

The following is a list of resources the readers may find helpful:

- Action Plan to Modernize GSSO Information Practices in Canadian EHRs
- BC Endocrine Standards
- Gender, diversity and inclusion statistics – Statistics Canada
- HL7 Informative Document: Gender Harmony-Modeling Sex and Gender Representation, Release 1
- Rainbow Health Ontario Trans Health Guide
- Sherbourne Hormone Therapy Guidelines
- Trans Care BC. Gender-affirming Care for Trans, Two-Spirit, Indigiqueer, and Gender Diverse Patients in BC: A Primary-Care-Toolkit
- World Professional Association on Transgender Health (WPATH) Standards (Version 8)

14.0 Definitions and Terminology

Standardization and precision in the use of sex and gender identity terminology will lead to a greater understanding and appropriate translation of GSSO terms. Terms used in this Standard and Guide align with definitions found in the following resources:

- Action Plan to Modernize GSSO Information Practices in Canadian EHRs → https://infocentral.infoway-inforoute.ca/en/resources/docs/sex-gender/sex-gender-action-plan/3496-gsso-action-plan-full-document
- BCCDC Public Health Language Guide → Language_Guide.pdf (bccdc.ca)
- Gender, Sex, and Sexual Orientation Resource → https://gsso.research.cchmc.org/#!/
- Gender-Based Analysis Plus (gov.bc.ca)
- Indigenous Gender Based Analysis Plus (IGBA+)
- Government of Canada: Gender and Sexual diversity glossary → https://www.btb.termiumplus.gc.ca/publications/diversite-diversity-eng.html#p
- Provincial Health Service Authority → Glossary | Trans Care BC
- Provincial Health Services Authority Glossary → Glossary of Terms - 3 sources.pdf (phsa.ca)
- Statistics Canada → http://www23.statcan.gc.ca/imdb/p3Var.pl?Function=DEC&Id=410445
- Trans Student Educational Resources → https://transstudent.org/about/definitions/

14.1. Terms and Definitions

The following terms and definitions are based on the cited literature and available resources:

Term	Definition
Asexual	A sexual orientation identity that refers to a person who feels little to no sexual attraction.
Bisexual	A sexual orientation identity that refers to a person who is sexually and/or romantically attracted to those of the same gender and to those of one or more other genders.
Cisgender	Refers to persons whose current gender aligns with their sex assigned at birth.
Digital Health Information Systems	Refers to electronic health records (EHR), electronic medical records (EMR), lab information systems and patient portal health records, among others. Broadly speaking, the term refers to the computerized component(s) of health information systems, distinct from manual or paper-based information systems.
Female	A category of biological sex, typically associated with XX chromosome complement but which is also influenced by gonadal development and other factors unrelated to the X chromosome.
Healthcare Workers	A category that can include clinicians, healthcare support staff, or anyone who supports or delivers healthcare services to patients directly or indirectly within the health system.
Gay	A sexual orientation identity that refers to a person who is sexually and/or romantically attracted to people of the same gender.
Gender Diverse	Gender diverse is an umbrella category that includes persons whose current gender identity is not cisgender or not exclusively male or female. The term refers to gender identities that demonstrate a diversity of expression beyond the binary construct. It includes persons who are reported as being unsure of their gender, persons who are reported as both male and female, or neither male nor female.

Term	Definition
Gender Identity	Refers to an individual's personal experience of being a woman, man, nonbinary or how the person prefers to self-describe. A person's current gender identity may differ from the Sex at Birth and may differ from what is indicated on their current legal documents (Gender Used). A person's gender identity may change over time.
Gender Expression	Describes how a person chooses to publicly present their gender, including behaviour and outward appearance. Gender expression should not be used to infer the gender or sexual orientation of an individual.
Heterosexual	A sexual orientation identity that refers to a person who identifies as one gender and is mainly attracted to people of the other gender.
Indigenous Peoples	An international term referring to the original people of a colonized land. In Canada, the term refers to distinct populations of people: First Nations (status and non-status), Métis, and Inuit. These large divisions of Indigenous Peoples are comprised of hundreds of individual nations, communities, and cultural groups. The term Indigenous people (with a lower case "people") refers to more than one Indigenous person rather than a collective group of Indigenous Peoples.
Indigiqueer	An Indigenous gender identity.
Lesbian	A sexual orientation identity that refers to a woman who is sexually or romantically attracted to people of the same gender.
Male	A category of biological sex, typically associated with XY chromosome complement but which is also influenced by gonadal development and other factors unrelated to X or Y chromosomes.
Man	A social construct, man is a gender identity typically situated within a binary complex of man/woman and is typically associated with masculine behaviors and social constructs or roles.

Term	Definition
Medical Gender Transition or affirmation	Refers to a process through which one aligns one's physical sex characteristics (e.g., through hormones, surgery) with one's gender identity. Transgender people may seek medical care such as hormone therapy or surgery to effect changes in their primary and secondary sex characteristics to resemble more closely those of the gender and sex with which they identify. Not all transgender people will seek a medical transition.
Nonbinary Non-Binary	An umbrella term that refers to persons whose gender identity is not exclusively man or woman.
Pansexual	A sexual orientation identity that refers to a person who is sexually or romantically attracted to people regardless of their sex or gender
Sex	Refers to categories based on biological and physiological characteristics and is usually recorded at birth based on observable external genitalia of the neonate.
Sex at Birth	The sex of a person at birth. Usually but not always determined by a clinician based on phenotypic (e.g., genitals or gonads), physiologic (e.g., hormone levels) and/or genetic characteristics. Most commonly, this is limited to phenotypic observations. Sex at Birth is typically recorded shortly after birth, usually by a clinician, and usually indicated in a legal system and/or document, like a birth certificate or provincial registry.
Sexual Orientation	Refers to who you’re attracted to and who you feel drawn to romantically, emotionally, and sexually.
Transgender	Refers to persons whose gender identity is not aligned with their Sex at birth.

Term	Definition
Two-Spirit	Refers to an Indigenous person who identifies as having both a masculine and a feminine spirit and is used by some Indigenous and First Nations people to describe their sexual, gender and/or spiritual identity. It reflects complex Indigenous understandings of gender roles, spirituality, and the long history of sexual and gender diversity in Indigenous cultures.
Undecided	In the context of this standard, this sexual orientation identity concept refers to a person who is undecided about their sexual orientation identity.
Woman	A social construct, woman is a gender identity typically situated within a binary complex of man/woman and is associated with feminine behaviors and social constructs/roles.

15.0 Related Standards

Type	Standard
National	• CIHI Reference Data Model Toolkit • CIHI Pan-Canadian Health Data Content Framework • Equity stratifiers | CIHI • Statistics Canada: ○ Gender of person ○ Sex (at birth) of person ○ Participate in the consultation on gender and sexual diversity statistical metadata standards
International	• Australian Government Guidelines • HL7 Informative Document: Gender Harmony- Modeling Sex and Gender Representation, Release 1 • National Health Service (NHS) - Gender Standards • Office of the National Coordinator for Health Information Technology (ONC) • OpenEHR archetypes

16.0 List of Acronyms

Acronym	Definition
BC	British Columbia
BCOHRC	BC’s Office of the Human Rights Commissioner
CIHR	Canadian Institutes of Health Research
CIS	Conformance and Integration Services
DHIS	Digital Health Information System
EHR	Electronic health record
EMR	Electronic medical record
FOIPPA	Freedom of Information and Protection of Privacy Act
GBA+	Gender-Based Analysis Plus
GSSO	Gender, sex, and sexual orientation
HL7	Health Level Seven International
HSIMIT	Health Sector Information Management/Information Technology
MoH	Ministry of Health
OCAP	Ownership, control, access, and permission
OCIO	Office of the Chief Information Officer
PIPA	Personal Information Protection Act

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