

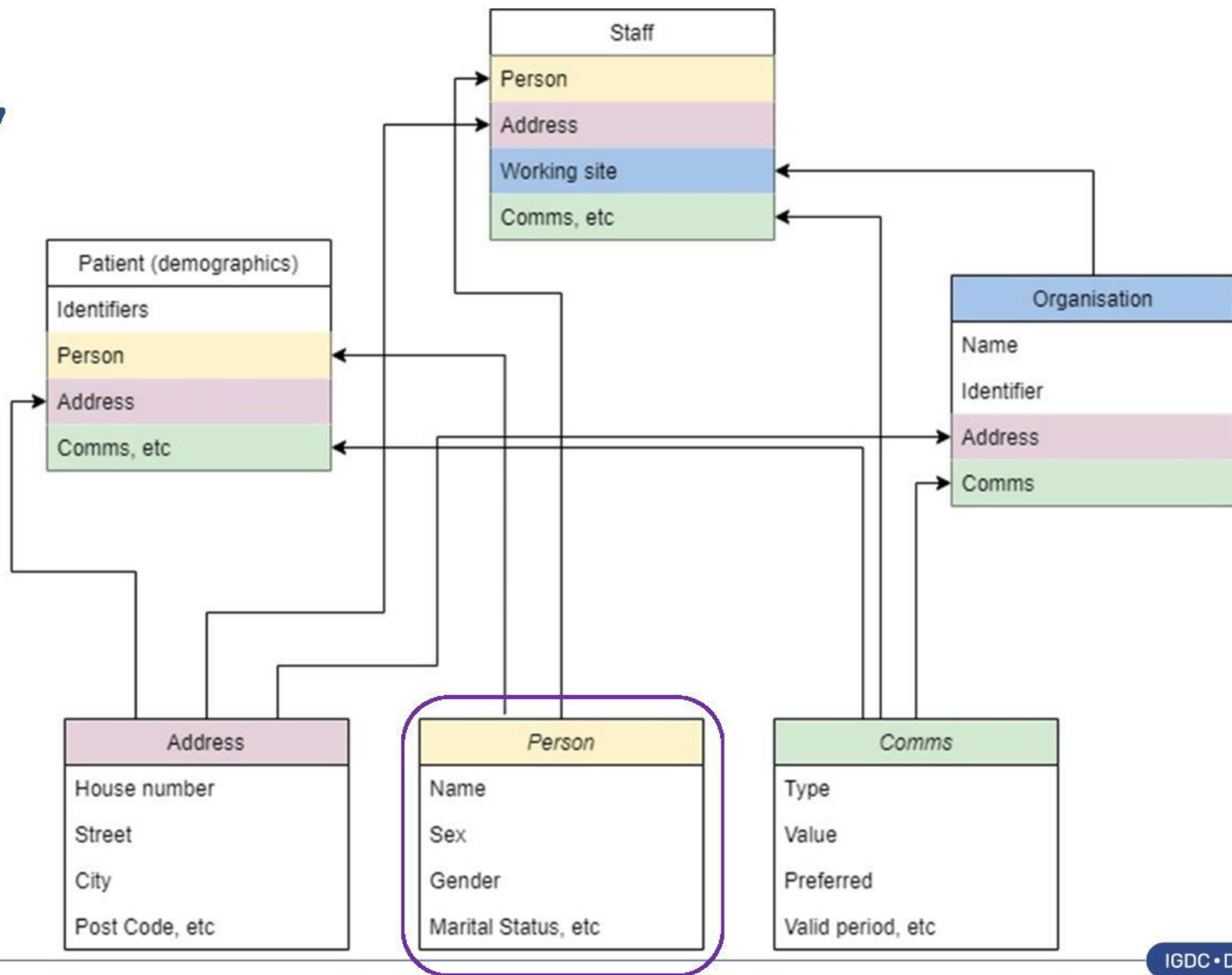
Standards engagement

Part II – Sex and gender data

22 – May – 2025

Strategy & Aim

Strategy



Purpose of this meeting

It is about the **model**, not the application.

It is about **safety** and **respect** for all.

It is a **proposal**, an opportunity to contribute.

Some historical factors

Gender Recognition Act (2004)

Gender Recognition Act 2004

UK Public General Acts > 2004 c. 7 > Consequences of Issue of... > Section 9

Table of Contents	Content	Explanatory Notes ?	More Resources ?
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What Version ? ✓ Latest available (Revised)		Changes over time for: Section 9 ?	

9

General

- (1) Where a full gender recognition certificate is issued to a person, the person's gender becomes for all purposes the acquired gender (so that, if the acquired gender is the male gender, the person's sex becomes that of a man and, if it is the female gender, the person's sex becomes that of a woman).

Opening options

▼ More Resources

9

General

- (1) Where a full gender recognition certificate is issued to a person, the person's gender becomes for all purposes the acquired gender (so that, if the acquired gender is the male gender, the person's sex becomes that of a man and, if it is the female gender, the person's sex becomes that of a woman).
- (2) Subsection (1) does not affect things done, or events occurring, before the certificate is issued; but it does operate for the interpretation of enactments passed, and instruments and other documents made, before the certificate is issued (as well as those passed or made afterwards).
- (3) Subsection (1) is subject to provision made by this Act or any other enactment or any subordinate legislation.

[◀ Previous: Provision](#)

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Equality Act 2010

Equality Act 2010

UK Public General Acts > 2010 c. 15 > Table of contents

Table of Contents | Content | Explanatory Notes | More Resources

Plain View | Print Options

What Version

- ✓ Latest available (Revised)
- Original (As enacted)

▼ Opening Options

▼ More Resources

Changes to legislation:
Equality Act 2010 is up to date with all changes known to be in force on or before 12 May 2025. There are changes that may be brought into force at a future date.

▼ View outstanding changes

Part 2 Equality: key concepts

Chapter 1 Protected characteristics

1. The protected characteristics
2. Age
3. Disability
4. Gender reassignment
5. Marriage and civil partnership
6. Race
7. Religion or belief
8. Sex
9. Sexual orientation

Unintended consequence:

- To avoid legal problems people stopped collecting Sex data and, instead, started collecting Gender data (as if these were interchangeable)

GRC

How many people have changed their legal gender?

Since the Act came into force, **4,910** trans people have been issued a Gender Recognition Certificate. **12%** of trans respondents to the National LGBT survey who had started or completed their transition had successfully obtained one, and **7%** of those who knew about them but did not have or had not applied for one said they would *not* be interested in obtaining one.



Government
Equalities Office

TRANS PEOPLE IN THE UK

What is trans?

Trans is a general term for people whose gender is different from the gender assigned to them at birth. For example, a trans man is someone that transitioned from woman to man. Trans people do not feel comfortable living as the gender that they were born with. They take serious, life-changing steps to change their gender permanently.

What is a gender change?

Changing gender involves social, medical, legal and administrative changes. Trans people can change their name and gender for almost all services without changing their legal gender. This includes passports and driving licences.

How many trans people are there?

We don't know. No robust data on the UK trans population exists. We tentatively estimate that there are approximately **200,000-500,000** trans people in the UK. The Office for National Statistics is researching whether and how to develop a population estimate.

Facts and Figures

41% of trans men and trans women responding to a Stonewall survey said they had experienced a hate crime or incident because of their gender identity in the last 12 months. They also found that **25%** of trans people had experienced homelessness at some point in their lives. Our national LGBT survey found similar results, with **67%** of trans respondents saying they had avoided being open about their gender identity for fear of a negative reaction from others.

How can you legally change your gender?

Trans people can change their legal gender by meeting the requirements set out in the Gender Recognition Act 2004. They then receive a Gender Recognition Certificate, by which their birth certificate is changed. The requirements are:

1. A medical diagnosis of gender dysphoria
2. A report from a medical professional detailing any medical treatment
3. Proof of having lived for at least two years in their acquired gender through, for example, bank statements, payslips and a passport
4. A statutory declaration that they intend to live in the acquired gender until death
5. If married, the consent of their spouse
6. Payment of a fee of £140 (or proof of low income for reduction/removal of the fee)
7. Submission of this documentation to a Panel, which the applicant does not meet in person

How many people have changed their legal gender?

Since the Act came into force, **4,910** trans people have been issued a Gender Recognition Certificate. **12%** of trans respondents to the National LGBT survey who had started or completed their transition had successfully obtained one, and **7%** of those who knew about them but did not have or had not applied for one said they would *not* be interested in obtaining one.

What steps are involved in a gender transition?

- 1 Names and pronouns on letters and utility bills
- 2 Gender for service providers including banks
- 3 Gender for employers and monitoring surveys
- 4 Gender in passports and driving licences

The individual makes these changes to their own accounts / documents

NOT regulated by the Gender Recognition Act 2004

- 5 Diagnosis of gender dysphoria, access to cross-sex hormones (from 16) and surgery (from 18)

The NHS decides

- 6 A new birth certificate for marriage and right pension provision

The Gender Recognition Panel considers the application

Gender Recognition Act 2004

Gender Recognition Act reform: consultation and outcome – 18/February/2022



Passports



Home Office

EU Settlement Scheme (interim guidance): Gender identity and sex markers on documents

Version v2.0

- Document conflates sex and gender.
- ICAO standards – options are M, F and X (which is optional)
- The UK follows the standard but does *not* issue passports with 'X'.
- This document calls it a **sex marker**, which is either male or female, that can be updated with a GRC.

Passports



- Conflates sex and gender
- *The customer's selection will appear as the **sex** M or F on the personal details page in the passport, which is in line with ICAO standards.*
- *Ask the customer to tell us what their current **gender** (male or female) is. This will be either their gender:*
 - *they were assigned at birth*
 - *in their last British passport*
 - *that was recognised by a Gender Recognition Certificate*

Sullivan Review – 19/March/2025



1. Shift in data collection: Many public bodies have stopped collecting data on biological sex, replacing it with self-declared gender identity.
2. Impact: This has caused significant issues in areas such as health, justice, education and the economy (unreliable data).
3. Healthcare : NHS records often lack data on biological sex. Sex can be changed on request without any requirement.
4. Recommendations: The review calls for the restoration of data standards and the collection of accurate sex data.

High Court ruling – 15/April/2025



Hilary Term
[2025] UKSC 16
On appeal from: [2023] CSIH 37

JUDGMENT

**For Women Scotland Ltd (Appellant) v The Scottish
Ministers (Respondent)**

before

Lord Reed, President
Lord Hodge, Deputy President
Lord Lloyd-Jones
Lady Rose
Lady Simler

**JUDGMENT GIVEN ON
16 April 2025**

Heard on 26 and 27 November 2024

Impacts on this standard:

- This standard does *not* include the application of the model.
- We are recommending *not* using the terms 'woman' or 'man'.

Government Statistical Service (GSS) Harmonisation Team workplan 2024

This working group states:

- *Sex: There is currently no harmonised standard on the topic of sex.*
- *Gender identity: we have archived our gender identity data harmonised standard while we work to develop new harmonised standards for sex and gender identity.*

Latest Update – Sex and gender identity

Work on the topics of sex and gender identity were paused from Summer 2023 until Autumn 2024, due to a series of reviews of gender identity data quality in the Census 2021 in England and Wales, which the gender identity harmonised standard was based on. This includes [ONS' review on quality of Census 2021 gender identity data](#) and [OSR's review of statistics on gender identity](#). An [independent review of data, statistics and research on sex and gender](#) has also been commissioned by Department for Science, Innovation and Technology (DSIT). Whilst this review has not been published yet, we are sharing our updated workplan and priority activities for these topics in line with the Office for Statistics Regulation's recommendation.

As of 12 September 2024, the gender identity estimates from Census 2021 are no longer [accredited official statistics](#) and are classified as [official statistics in development](#). The new classification is more consistent with the 'under development' status of the current Gender Identity harmonised standard.

Our workplan, including phases of development, follow. Timescales for each phase of development are provided in the final section of this plan.

The model

Person

- ↳ Sex at birth (1..1)
- ↳ Gender identity (0..*)
- ↳ Administrative gender (0..1)
- ↳ Legal sex (0..1)
- ↳ Personal pronouns (0..1)

Sex at birth

Synonyms	Biological sex ^(*1)
Definition	The sex of the person at the moment of their birth. ^(*2)
Cardinality	1.1 (see Phased implementation slide)
Datatype/Format	Coding
Namespace	https://snomed.info/sct
Code/Display	See following slides
Constraints	No additional constraints

Additional Guidance
Initially, this item will be optional to avoid spurious data. Data entry in this field MUST be done with care.
Ideally, a SSOT should be achieved and specific systems have the option to add this data item (eg: maternity systems for newborns, GPs for overseas & Scottish, Genetic results lab)
^(*1) There are very rare instances in which the sex recorded at birth or perinatal is identified to be incorrect in puberty. Sometimes, the word 'sex' alone is used – we qualify it to differentiate it from the legal sex.
^(*2) not to be used in unborn babies.

Female Sex

Doesn't have a Sex-determining region Y (SRY) gene.

46XX – typical female

Conditions occurring in 46XX typical females that may lead to confusion

- Polycystic ovary syndrome (PCOS): can cause excess androgen production in adulthood (increased body hair and other masculine features)
- Clitoromegaly: in some babies can cause initial confusion with a penis
- Congenital Adrenal Hyperplasia (CAH): excess androgen production
- Late onset Congenital Adrenal Hyperplasia (CAH): can cause androgen excess but does not affect sex development
- Mayer Rokitansky Küster Hauser syndrome: the vagina and uterus are underdeveloped or absent

Male Sex

Has a Sex-determining region Y (SRY) gene (usually in Y chromosome)

46XY – typical male

Conditions occurring in 46XY typical males that may lead to confusion

- Hypospadias - condition in which the opening of the urethra is on the underside of the penis instead of at the tip. Occurs mostly in 46XY males. It can occur in males with other karyotypes.
- Micropenis – generally occurs due to abnormal hormonal levels.

Variations of sex development (VSD)

Conditions with chromosomal and genetic alterations in the sex chromosomes that result in atypical physical characteristics

Genetic females

- Turner syndrome = 45X
- Swyer Syndrome = 46XY Gonadal Dysgenesis – the SRY gene is defective or missing, leading to ovarian-like gonads and female development

Genetic males

- Androgen Insensitivity Syndrome (AIS) = 46XY, insensitive to androgens. In “Complete” cases (CAIS), the individual is phenotypically a woman, whereas in “Partial” (PAIS) the individual has more ambiguous genitalia
- Klinefelter Syndrome = 47 XXY and other less common variations like 48XXXY.
- 5 α -reductase deficiency = 46XY with low active testosterone
- XX Male Syndrome = 46XX with SRY gene translocation. SRY gene is misplaced to an X chromosome leading to male development.
- Mixed Gonadal Dysgenesis – 45X/46XY – a mosaic leading to ambiguous or asymmetrical gonadal development
- Ovo testicular disorder 46XX (60-70%), 46XY (10-20%), mosaics of 45X/46XX (10-20%) – individuals have both types of tissues.

Value set

- 1) Values accepted are Female, Male, Indeterminate.
- 2) Indeterminate to be used during the investigation period only.
- 3) Intersex NOT to be used to avoid confusion.

SNOMED CT International

"Parent concept"

429019009 |Finding related to biological sex (finding)|

Code	Value
248152002	Female
248153007	Male
32570681000036106	Indeterminate sex
32570691000036108	Intersex

Mapping table

Data values	Core Reference Data Standard (CRDS)	SNOMED CT (International)	FHIR (R4)
Male (sex)	M Male	248153007 Male	M Male
Female (sex)	F Female	248152002 Female	F Female
Indeterminate	U Indeterminate	32570681000036106 Indeterminate sex	UN Undifferentiated

NB: Currently, Indeterminate in CRDS is stated to be used for unborn babies

Gender identity

Synonyms	Identified gender ^(*3)
Definition	A person's sense or perception of their gender.
Cardinality	0..*
Datatype/ Format	Coded + Free text
Namespace	https://snomed.info/sct
Code/ Display	See following slides
Constraints	No additional constraints

Additional Guidance
^(*3) Sometimes, this is only called 'Gender', but we use the qualifying 'identity' to ensure clarity.
Aim is to code the most frequent gender identities, but given the range, the free-text will allow to capture the correct data.
Data analysis will identify terms that would benefit from coding.

Value Set

- 1) 100+ gender identities
→ difficult to code.
- 2) Relevance of coding to obtain data that can be acted on.
 - US exemplar – Meaningful Use 3.
- 3) 'Other' → naming convention in IA

SNOMED CT International


"Parent concept"



285116001 |Gender identity finding (finding)|

Code	Display
446151000124109	Identifies as male gender
446141000124107	Identifies as female gender
33791000087105	Identifies as nonbinary gender
Other*	as free text

Display

Parents

➤  Gender identity finding (finding)

 Identifies as male gender (finding)  

SCTID: 446151000124109

446151000124109 | Identifies as male gender (finding) |

- Identifies as male gender (finding)
- Identifies as male gender
- Male identity
- Male gender identity

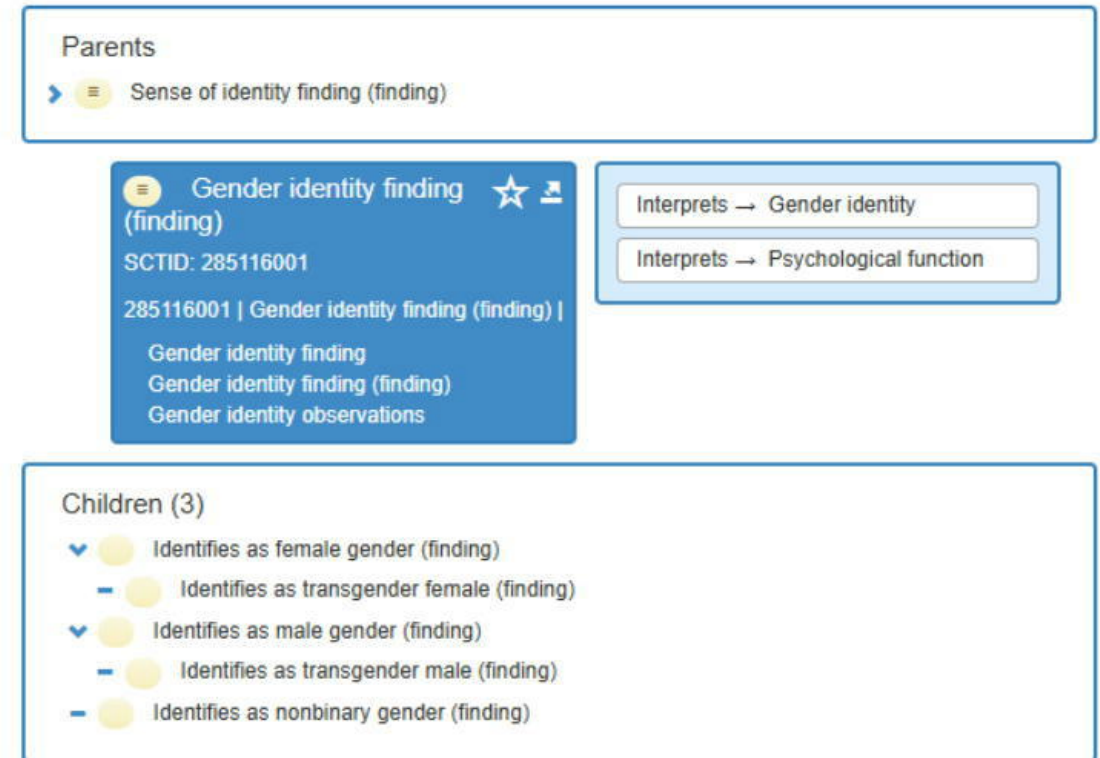
Interprets → Psychological function

Interprets → Gender identity

- These values are nested under the same concept ID (synonyms).
- Any of them can be used interchangeably.
- For interoperability, the mandate remains to send the code.

GDPR considerations

- This standard proposes *not* using the term “trans” as it discloses the sex, which is a protected characteristic.
- Consideration: include it in the future, if the person wishes to disclose and use the ‘transgender’ term.
- This will be a question in the impact assessment.



Administrative gender

Synonyms	"Recorded sex or gender"
Definition	The gender that the patient is considered to have for administration and record keeping purposes.
Cardinality	0..1 (see Phased implementation slide)
Datatype/Format	Coding
Namespace (System)	http://hl7.org/fhir/administrative-gender
Code/Display	See namespace
Constraints	No additional constraints

Additional Guidance
Systems should not infer any specific clinical meaning from this data item
FHIR values as there are no SNOMED CT values for this concept.

Value Set

- 1) This is a FHIR value set
- 2) HL7 has a mapping from FHIR to V2 and V3

FHIR R4

Administrative gender

Code	Display	Definition
male	Male	Male.
female	Female	Female.
other	Other	Other.
unknown	Unknown	Unknown.

<https://hl7.org/fhir/valueset-administrative-gender.html>

Legal sex

Synonyms	-
Definition	The sex as presented in a birth certificate; this can be updated when acquiring a GRC
Cardinality	0..1
Datatype/Format	Coding
Namespace	http://hl7.org/fhir/administrative-gender
Code/Display	See namespace
Constraints	No additional constraints

Additional Guidance

The recommendation is to use the same values and codes as for Administrative Gender.

FHIR values as there are no SNOMED CT values for this concept.

Personal pronouns

Synonyms	Third person and possessive pronouns
Definition	Third person pronouns are used to refer to people that are not the speaker or the person being spoken to. Possessive pronouns indicate ownership or belonging.
Cardinality	0..1
Datatype/ Format	Coded + Free text
Namespace	http://terminology.hl7.org/ValueSet/pronouns
Code/ Display	See namespace
Constraints	No additional constraints

Additional Guidance

FHIR values as there are no SNOMED CT values for this concept.

The FHIR values refer to LOINC values.

Value Set

- 1) This is a LOINC List (LL) with LOINC Answers (LA).
- 2) FHIR includes the first three (highlighted in yellow)

<https://loinc.org/LL5144-2>

LOINC

LL5144-2 | Personal pronouns (Answer list)

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

Phased implementation

Current stage

Data item	Cardinality
Sex or Gender	varies

Intermediate stage

Data item	Cardinality
Administrative gender	1..1
Sex at birth	0..1
Gender identity	0..1
Legal sex	0..1
Personal pronouns	0..1

Final stage

Data item	Cardinality
Administrative gender	0..1
Sex at birth	1..1
Gender identity	0..*
Legal sex	0..1
Personal pronouns	0..1

Step 1 - Minimum for demographic data

Administrative gender.
Sex at birth.
Gender identity.

Step 2 - Addressing the person correctly

Preferred name.
Personal pronouns.
Legal sex.

Step 3 - Biological data

Organ inventory.
Hormonal profile.
Genetic analysis.

Step 4 - Psychosocial data


Sexual orientation.
Sexual behaviours.
Gender category.
Etc.

FUTURE WORK

Breasts ☐ Present ☐ Absent
☐ Chest reconstruction
☐ Bilateral mastectomy
☐ Unilateral mastectomy, R
☐ Unilateral mastectomy, L
☐ Breast augmentation/implants
Uterus ☐ Present ☐ Absent
☐ Hysterectomy—cervix removed
☐ Hysterectomy—cervix remains
Ovaries ☐ Present ☐ Absent
☐ Bilateral salpingo-oophorectomy
☐ Unilateral salpingo-oophorectomy, R
☐ Unilateral salpingo-oophorectomy, L
Cervix ☐ Present ☐ Absent
Vagina ☐ Present ☐ Absent
☐ Colpocleisis—closure of the vagina
☐ Vaginoplasty
Penis ☐ Present ☐ Absent
☐ Phalloplasty/penile implant
☐ Metoidioplasty
☐ Erectile device
☐ Penectomy
Testes ☐ Present ☐ Absent
☐ Testicular implant(s)
☐ Bilateral orchiectomy
☐ Unilateral orchiectomy, R
☐ Unilateral orchiectomy, L
Urethra ☐ Present ☐ Absent
☐ Urethral lengthening
Prostate ☐ Present ☐ Absent
☐ Prostatectomy

REFERENCES

ISO Standard



TECHNICAL REPORT ISO/TR 9143:2023

Edition 1
2023-12

Health informatics — Sex and gender in electronic health records

ISO

Published (Edition 1, 2023)

Read sample

← TC ← ISO/TC 215

ISO/TR 9143:2023

Health informatics — Sex and gender in electronic health records

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Section 1h: Cross-paradigm/Domain Analysis Models

HL7 Informative Document: Gender Harmony - Modeling Sex and Gender Representation, Release 1

DESCRIPTION

Health care is increasingly turning to technology to help improve systems and processes to benefit patients and their health. Ongoing efforts supported by governing agencies and standards committees are responding to the demonstrated need through standards that allow for seamless integration of patient information between systems.



It is imperative that both sex and gender vocabulary be formally integrated into clinical care because they are not interchangeable. Both influence health outcomes. Gender-marginalized individuals face significant barriers to adequate and culturally responsive healthcare, leading to numerous health disparities. By adopting structured data sets, agnostic systems will be better equipped to transmit (share) and accept data elements that will improve the accuracy of patient information. Furthermore, standardizing data enables information to be combined with other data sources used to evaluate clinical outcomes. While data collection and documentation are critical factors in clinical decision-making, these new data will also promote important dialogue between clinicians and patients. Ultimately, this will assist with improved quality of care, reduced clinician burden and less fragmentation of a person's clinical record.

Currently, it is common that a single data element is used to capture both sex and gender information, often assuming these two items are one unified idea. This specification challenges that notion and proposes that independent consideration of sex and gender, and the assessment of their differences promotes the health of women, men, and people of diverse gender identities of all ages, avoiding systematic errors that generate results with a low validity (if any) in clinical studies. The Gender Harmony model describes an approach that can improve data accuracy for sex and gender information in health care systems.

https://www.hl7.org/implement/standards/product_brief.cfm?product_id=564

<https://build.fhir.org/ig/HL7/fhir-gender-harmony/model.html>

HL7 – GHP


HL7 Cross Paradigm Implementation Guide: Gender Harmony – Sex and Gender Representation, Edition 1


1.0.0 - release

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This page is part of the HL7 Cross Paradigm IG: Gender Harmony – Sex and Gender Representation (v1.0.0: informative1 – Informative) based on FHIR v5.0.0. This is the current published version. For a full list of available versions, see the [Directory of published versions](#).

1 Home

Official URL: http://hl7.org/xprod/ig/uv/gender-harmony/ImplementationGuide/hl7.xprod.uv.gender-harmony	Version: 1.0.0
Active as of 2023-09-29	Computable Name: CrossParadigmGenderHarmony

1.1 Introduction

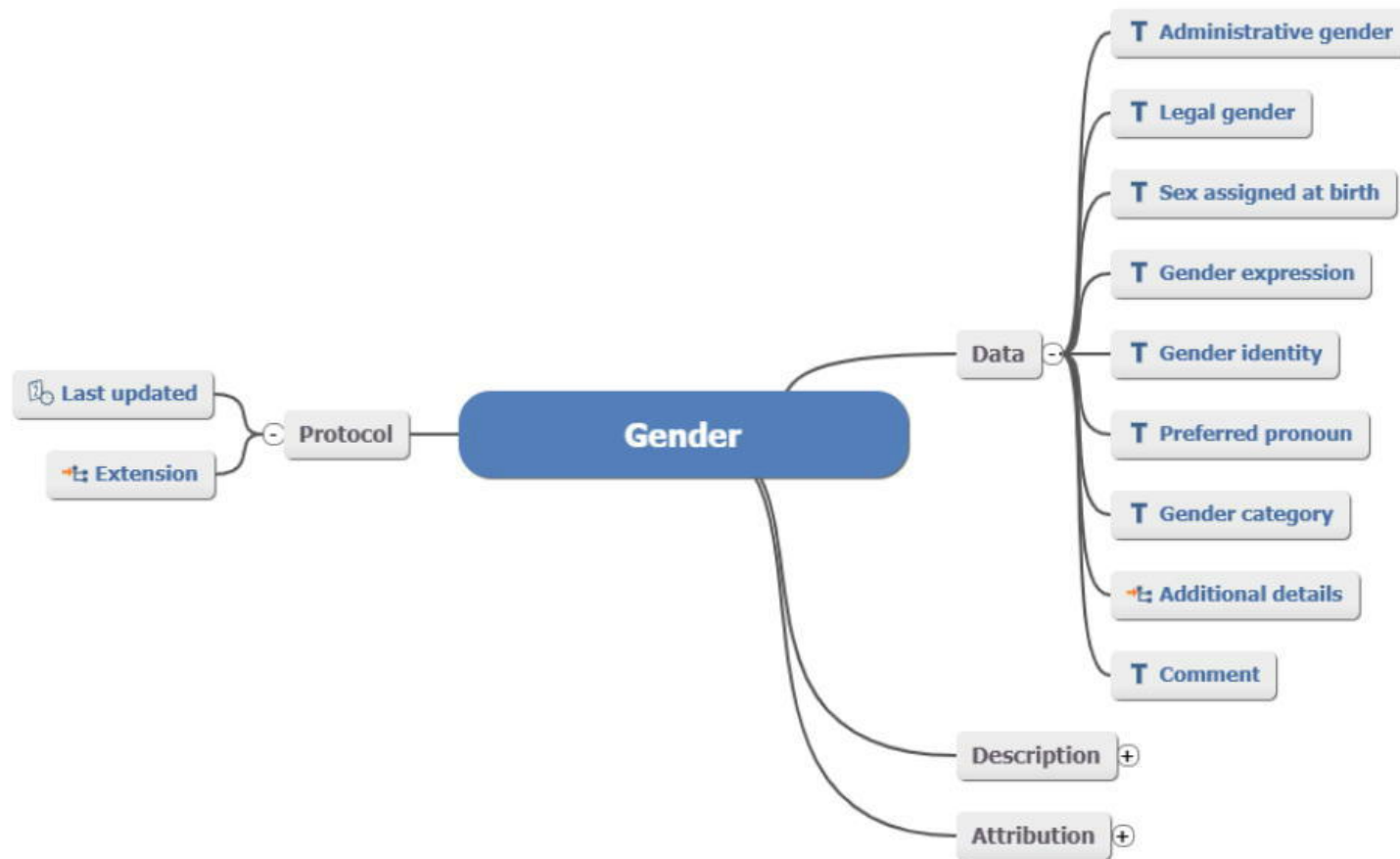
This universal-realm Implementation guide describes the changes Incorporated in HL7 product family specifications that are aligned with the [HL7 Informative Document: Gender Harmony – Modeling Sex and Gender Representation, Release 1](#) published in 2021. Based upon ballot comments and participant feedback, this publication and the associated V2, CDA, and FHIR specifications include minor improvements when compared to the logical model described in the 2021 specification. These changes are described in the [Model](#) section of this specification.

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This implementation guide contains *Informative* content discussing the overall Gender Harmony Project (GHP) approach intended to provide definitive guidance on how to exchange clinical sex and gender affirming information using HL7 models. We also provide examples that align with that guidance. The content of this guide must be viewed as accompanying the gender harmony content within the product family-specific specifications found elsewhere. Each of these is described in more detail in other pages of this guide.

openEHR – Gender evaluation



REFERENCES

The following resources were referenced when drafting this standard:

1. Wales FHIR Patient Profile and FHIR International Person Resource
2. Data Standards Wales Core Reference Data Standard (Page 8)
3. NHS Wales Data Dictionary
4. NHS England Data Dictionary
5. Public Health Scotland Data Dictionary
6. openEHR – Gender Evaluation archetype
7. PRSB Core Information Standard
8. ISO/TR 9143:2023 – Health informatics – Sex and gender in electronic health records
9. Gender Harmony Project
10. British Columbia (Canada) Standard (refer to pages 24–26 for graphs)
11. Additional consulted standards: DICOM, OMOP, Sparked (Australia), Meaningful Use 3, national standards.



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