

## New concept

### Administrative Sex

<b>Author</b>	<b>Katie Kalt, Julien Ehram</b>	<b>Date of request updated</b>	<b>3<sup>rd</sup> June 2023</b>
<b>Project</b>	General interest	<b>Contact</b>	DCC
<b>Dataset release</b>	2024.1	<b>Consulted expert</b>	

#### 1 Change request input / rationale

Defined as the gender used for administrative purposes, but SNOMED codes for value set changed to reflect gender identity, however Administrative sex/gender is generally based on biological sex, which is what is most often present on official documents.

Change needed either in definition of concept or value set.

Possibilities:

- descendants of 429019009 [Finding related to biological sex (finding)]
- descendants of 285116001 [Gender identity finding (finding)]

#### 2 Comparison to other standards/data models

To clarify the definitions used in standards we need to define first two terms:

Term Gender vs. Sex

**Gender:** Gender is usually used to define the "Gender Orientation" of a person.

Based on social, psychological, and cultural constructs, can vary and change between societies  
Not necessarily defined by biological sex

**Sex:** Sex refers to the biological and physiological characteristics of a person.

This could be based on Karyotypic definitions or available organs of a person.

Sex is usually also used in official documents.

Usually assigned at birth, based on the physical characteristics.

**FHIR** Defines the gender as AdministrativeGender, however, uses the historic definition of male, female, other and unknown as they are easily available information from the patient's official

documents.

The allocation of the AdministrativeGender is usually done at birth based on the sexual organs of a baby. However, there are also children born as intersex where the parents assign a sex together with the doctor but this does not mean that the sex organs are also assigned to the corresponding sex.

Issue is that they mix the term gender with sex and often the meaning does not relate to the medical requirements.

Our current version is based on the FHIR AdministrativeGender.

Canadian Institute of Health Research (<https://cihr-irsc.gc.ca/e/48642.html>)

Sex is usually categorised as female or male but there is variation in the biological attributes that comprise sex and how those attributes are expressed. Gender refers to the socially constructed roles, behaviours, expressions and identities of girls, women, boys, men, and gender diverse people.

Possible definitions of gender/sex:

Type	Determination	Values	Medical Purpose
Administrative	Sex in official Documents (ID, Passport)	usually M or F, if others it is usually mixed with gender identification	last resort if no other determination is available, usually not always correct in medical terms.
Karyotypic	Chromosomes	<b>non conclusive list of examples:</b> XX, XY X&Y chromosome variations in males include: <ul style="list-style-type: none"> <li>• 47,XXY (Klinefelter syndrome)</li> <li>• 47,XYY</li> <li>• 48,XXYY</li> <li>• 48,XXXY</li> <li>• 49,XXXXY</li> </ul> X chromosome variations in females include: <ul style="list-style-type: none"> <li>• 45,X (Turner syndrome)</li> <li>• 47,XXX (Trisomy X or Triple X)</li> <li>• 48,XXXX (Tetrasomy X)</li> <li>• 49,XXXXX (Pentasomy X)</li> </ul>	genetic sex
Physical / Anatomy	What body parts does the person have.	vagina, ovaries, penis, prostate, breasts, etc.	Treatment of problems and conditions in relation to sexual organs

Gender Identification	How the person identifies her/himself	female, male, transgender, fluid, non-binary, none, (intersex), two-spirit (2S), etc.	Treatment of Gender Dysphoria and similar conditions
-----------------------	---------------------------------------	---	--

### 3 Change content

#### 3.1 Currently released concept

Concept or concept compositions or inherited	General concept name	General description	Contextualized concept name	Contextualized description	Type	Standard	Value set or subset	Meaning binding
Concept	Administrative Gender	the gender of the individual used for administrative purposes	Administrative Gender	the gender of the individual used for administrative purposes				SNOMED CT: 365873007  Gender finding (finding)
composedOf	Gender	code, name, coding system and version describing the concept	Gender	administrative gender according to the valueset	Code	SNOMED CT	446151000124109  Identifies as male gender (finding) ; 446141000124107  Identifies as female gender (finding) ; 74964007  Other (qualifier value) ; 261665006  Unknown (qualifier value)	
composedOf	Record datetime	datetime the concept was recorded	Record datetime	datetime at which the gender started to be valid	Temporal			

### 3.2 Proposed new concept

Concept or concept compositions or inherited	General concept name	General description	Contextualized concept name	Contextualized description	Type	Standard	Value set or subset	Meaning binding	Cardinality for composedOf
Concept	<b>Administrative Sex</b>	the <b>sex</b> of the individual used for administrative purposes	Administrative Sex	the <b>sex</b> of the individual used for administrative purposes derived from official documents					
composedOf	<b>code</b>	coded information specifying the concept	<b>sex</b>	administrative <b>sex</b> according to the valueset	Code	SNOMED CT	<b>248152002   Female (finding)  </b> <b>248153007   Male (finding)  </b> <b>32570681000036106   Indeterminate sex (finding)  </b>		1:1
composedOf	record datetime	datetime the concept was recorded	record datetime	datetime the administrative sex was recorded	temporal				0:1

General concept name	Cardinality for concept to Administrative Case	Cardinality for concept to Data Provider Institute	Cardinality for concept to Subject Pseudo Identifier	Cardinality for concept to Source System
<b>Administrative Sex</b>	-	-	1:1	1:1

## 4 Pros and cons

### 4.1 Advantages

More correct naming, description and value set.

### 4.2 Disadvantages

## 5 Impact on SPHN Dataset

None.

## 6 Discussion

From the four types of gender/sex identification in section 2 it is proposed to:

- a. Change Administrative gender to Administrative sex according to this change request.
- b. Introduce Karyotypic Sex concept, in preparation by the OMICS Sub-Group.
- c. Not provide a concept for Gender at the moment as there is no need stated by any NDS/DEM project. The value set is complex and is usually not recorded in hospitals, except in conjunction with gender dysphoria treatment.
- d. Optionally, implement a change request to BodySite to document present or absent anatomical parts.

Data availability:

- The AdministrativeSex is usually available as in 99.9% of the cases. This is taken from the official documents. However, the term AdministrativeSex would be more correct.
- Karyotypic sex is only available if a genome was sequenced.
- BodyStructure is usually not defined/documented but can be derived from certain diagnosis or procedures. However, this cannot guarantee that the sex is correctly identified, and it depends on how it was documented. E.g. Breast Implant could also occur with a trans woman and a trans man may not have the female anatomy of a woman. As a result, this is more a documentation of available sexual organs and not a determination of sex.
- Gender Identity is only documented in the treatment of trans people or in a psychiatric/psychological unit.

## 7 Example

### AdministrativeSex

code:

identifier: 248152002

name: Female (finding)

coding system and version: SNOMED-CT-2023-07-31

record datetime: 2023.08.13T14:14:00.00000