

*HL7 Gender Harmony Project, Official Response to USCDI v3*

The HL7 Gender Harmony Project (GHP) officially recommends the following, regarding alignment with, and full consideration of, the Gender Harmony model.

The first grouping of recommendations (A) relate to existing items within the USCDI v3 draft. These are already implemented in some form or another in most systems, or have a form within the USCDI v3 draft already:

1. We recommend that “Gender Identity” values, as a property of “Patient Demographics”, be aligned with the minimum value set put forward in the HL7 Gender Harmony Project ballot. *Please see A1, below.*
2. We recommend that if “Sex (Assigned at Birth)”, as a property of “Patient Demographics”, is included that it be stated as a subtype of “Recorded Sex or Gender” (RSG) and aligned with the minimum value set put forward in the HL7 Gender Harmony Project ballot. We would like to note that “Sex (Assigned at Birth)” could be more accurately and reproducibly be restated as “Gender Marker on Original Birth Certificate”. However, we would also note that, although “Sex (Assigned at Birth)”, itself more accurately termed “assigned gender at birth”, is a common data element in a number of jurisdictions, it currently lacks a consistent definition from jurisdiction to jurisdiction and is open to clinically dangerous misuse. USCDI v3 would need to **seriously** consider any and all use cases wherein such an element would be useful, that are not adequately covered by “Sex For Clinical Use” (SFCU). *Please see A2, below.*
  - a. As an RSG, “Gender Marker on Original Birth Certificate” could use a template as follows if necessary for exchange:

Example	Context
<p>RSG {</p> <p><b>Source RSG:</b> M</p> <p><b>International Equivalent RSG:</b> M</p> <p><b>Record Description:</b> Original birth certificate</p> <p><b>Acquisition Date:</b> 10-20-2022</p> <p><b>Validity Period:</b> 01-30-1987 – 10-11-1999</p> <p><b>Jurisdiction:</b> Los Angeles County, California</p> <p><b>Source Field Name:</b> Gender marker on original birth certificate</p> <p><b>Source Field Description:</b> One’s gender marker as it appears on their original birth certificate.</p> <p>}</p>	<p><b>Source RSG:</b> This is the original value on the document; usually M, F, and X, but could vary in other regions (sometimes ‘D’ is used in Germany, for instance).</p> <p><b>International Equivalent RSG:</b> This is the translated value for international use, if necessary. We offered the minimum set used by the International Civil Aviation Organization (ICAO) in our ballot.</p> <p><b>Record Description:</b> Description of the record from which the Source RSG originated.</p> <p><b>Acquisition Date:</b> The date that the source RSG was recorded in the system.</p> <p><b>Validity Period:</b> The period from which the birth certificate was issued until the date the birth certificate was superseded (if that’s the case).</p> <p><b>Jurisdiction:</b> The jurisdiction in which the birth certificate was issued.</p> <p><b>Source Field Name:</b> The name as it appears on the source document or in the source system.</p> <p><b>Source Field Description:</b> The description of the source field, could provide a link to more in-depth description as well.</p>

The second grouping of recommendations (B) relate to items which currently do not exist in the USCDI v3 draft. These recommendations are newer, and not many systems have implemented them yet; for this reason, they are recommended for either Level 1 or Level 2:

1. Another form of RSG should be included in the “Health Insurance Information” object, being “Gender Marker on Health Insurance”, is recommended for Level 2. *Please see B1, below.*
2. We recommend that a form of “Sex For Clinical Use” (SFCU) be included within “Clinical Tests”. It could be called “Sex for Clinical Test” and is recommended for Level 1. *Please see B2, below.*
3. We recommend that a form of “Sex For Clinical Use” (SFCU) be included within “Diagnostic Imaging”. It could be called “Sex for Diagnostic Imaging” and is recommended for Level 1. *Please see B3, below.*
4. We recommend that a form of “Sex For Clinical Use” (SFCU) be included within “Laboratory”. It could be called “Sex for Laboratory Use” and is recommended for Level 1. *Please see B4, below.*
5. We recommend that a form of “Sex For Clinical Use” (SFCU) be included within “Procedures”. It could be called “Sex for Procedure” and is recommended for Level 1. *Please see B5, below.*
6. We recommend that “Third-Person Pronoun” be included within “Patient Demographics” and is recommended for Level 2. Currently, the HL7 GHP only handles English language pronouns, but future instances could include pronouns in other languages. *Please see B6, below.*
7. We recommend that “Name to Use” be included within “Patient Demographics” and is recommended for Level 2. *Please see B7, below.*
8. We recommend that “Care Team Member Name to Use” be included within “Care Team Member(s)” as a form of “Name to Use” and is recommended for Level 2. *Please see B8, below.*
9. We recommend that “Care Team Member Third-Person Pronoun” be included within “Care Team Member(s)” as a form of “Third-Person Pronoun” and is recommended for Level 2. *Please see B9, below.*

The third grouping of recommendations (C) are based on general recommendations substantiated in literature, which should be considered in the U.S. context:

1. For “Gender Identity” in HL7, there are minimum of four required values. It is **highly** recommended that jurisdictions consider if other values are useful and accurate in that jurisdiction or any of its sub-jurisdictions, and for individual sub-jurisdictions to have some level of autonomy in determining which additional options may work best for them.
  - a. For instance, it may make sense for the state of Hawaii to include māhū, but that determination should be made in that jurisdiction.
  - b. If a jurisdiction includes another option (such as māhū) and another jurisdiction does not have that additional option, the option should be translated into a string within the “Another gender identity not listed, please specify:” option.
  - c. Some options which should be considered by the United States and its sub-jurisdictions include, but are not limited to: [Two-Spirit](#), [Māhū](#), [Muxe](#), and [Palao’ana](#). However, adding these options requires additional input from specific local communities which cannot be provided by the HL7 GHP.
  - d. We also suggest removal of “transgender female” and “transgender male” (and their variants) as options for the “Gender Identity”; our reasoning for this is laid out within the HL7 GHP ballot, as well as within [Kronk et al \(2021\)](#).

- e. We further suggest changing “genderqueer” to “nonbinary” to better align with the HL7 GHP. Genderqueer is not synonymous with nonbinary. Unlike genderqueer, nonbinary has shown a steady-state in regard to usage, [in the period from 2015 to 2021](#) (in 2021, 30,405 individuals used the term nonbinary in the linked survey, for instance). In June 2021, the Williams Institute found that [more than 1 million Americans identify as nonbinary](#).
  - f. We suggest that gender identity always be listed above any other construct in patient demographics, in line with [current recommendations](#). Inclusion of gender identity in the model in the first place, as mentioned in the HL7 ballot, involves respect for patients. Consideration “sex assigned at birth”, or any related datum from a limited time point in someone’s life, over one’s current gender identity is disrespectful at best.
  - g. We suggest that additional options for all fields beyond the minimum required HL7 set, including those used with gender identity, be reassessed in a timely manner, such as every 2 years or every 5 years.
  - h. We also suggest that the system be able to accept more than one value simultaneously, as many individuals identify with multiple gender identities, such as bigender and genderfluid individuals.
2. While sexual orientation is not currently within the scope of the HL7 Gender Harmony Project, this may change in the future, and we would like to note that it may be advantageous to include “Asexual” as an option, as research has shown that anywhere from [1 percent](#) to [4 percent](#) of Americans identify as asexual. *Please see C1, below.*
- a. Additionally, some systems include Two-Spirit as a sexual orientation identity, which may or may not be appropriate. As stated above, inclusion of Two-Spirit as an option requires additional input from local Indigenous communities which cannot be provided by the HL7 GHP. Further, it should be noted that some Indigenous persons who are not Indigenous American use the term Two-Spirit as well, such as some Indigenous Australians and Torres Strait Islanders, and some Māori.
3. The HL7 GHP does not specifically cover intersex or use the term intersex [because intersex is usually not considered a Gender Identity or RSG datum](#). Additionally, most intersex conditions can be coded more specifically in other existing coding systems. If USCDI v3 wants to cover intersex versus non-intersex (sometimes called endosex or perisex) status under “Patient Demographics”, another entity not in GHP would be necessary. If something like this were to be added, it could be coded using example questions and response sets put together by [interACT](#), using a label like “Sex Dyadicity”, “Intersex Status”, or something of the like. Whether or not USCDI v3 makes this decision or includes anything of this nature is outside the scope of the HL7 GHP, however. *Please see C2, below.*

*Suggested Alignments and Additions*

**A1. Gender Identity, aligned with Gender Identity in HL7 GHP**

<b>Final Recommendation for USCDI v3</b>	<b>Alignment with HL7</b>	<b>Current USCDI v3 Draft</b>
Male	M	Male
Female	F	Female

		Female-to-Male (FTM)/Transgender Male/Trans Man
		Male-to-Female (MTF)/Transgender Female/Trans Woman
Nonbinary	X	Genderqueer, neither exclusively male nor female
Exploring or questioning gender identity		
Another gender identity not listed, please specify:	nullFlavor OTH	Additional gender category or other, please specify
Choose not to disclose	nullFlavor ASKU	Choose not to disclose
Unknown	nullFlavor UNK	

**A2. Gender Marker on Original Birth Certificate, formerly “Sex (Assigned at Birth)”, aligned with Recorded Sex or Gender in HL7 GHP**

Final Recommendation for USCDI v3	Alignment with HL7	Current USCDI v3 Draft
Female	F	Female
Male	M	Male
X	X	
Additional gender marker not listed, please specify:	nullFlavor OTH	
Choose not to disclose	nullFlavor ASKU	
Unknown	nullFlavor UNK	Unknown

**B1. Gender Marker on Health Insurance, aligned with Recorded Sex or Gender in HL7 GHP**

Final Recommendation for USCDI v3	Alignment with HL7	Current USCDI v3 Draft
Female	F	Female
Male	M	Male
X	X	
Additional gender marker not listed, please specify:	nullFlavor OTH	
Unknown	nullFlavor UNK	Unknown

**B2. Sex for Clinical Test, aligned with Sex for Clinical in HL7 GHP**

Final Recommendation for USCDI v3	Alignment with HL7	Current USCDI v3 Draft
Female	F	
Male	M	
Unknown	nullFlavor UNK	
Something else, please specify:	nullFlavor OTH	

**B3. Sex for Diagnostic Imaging**, aligned with *Sex for Clinical* in HL7 GHP

Final Recommendation for USCDI v3	Alignment with HL7	Current USCDI v3 Draft
Female	F	
Male	M	
Unknown	nullFlavor UNK	
Something else, please specify:	nullFlavor OTH	

**B4. Sex for Laboratory Use**, aligned with *Sex for Clinical* in HL7 GHP

Final Recommendation for USCDI v3	Alignment with HL7	Current USCDI v3 Draft
Female	F	
Male	M	
Unknown	nullFlavor UNK	
Something else, please specify:	nullFlavor OTH	

**B5. Sex for Procedure**, aligned with *Sex for Clinical* in HL7 GHP

Final Recommendation for USCDI v3	Alignment with HL7	Current USCDI v3 Draft
Female	F	
Male	M	
Unknown	nullFlavor UNK	
Something else, please specify:	nullFlavor OTH	

**B6. Third-Person Pronoun**, aligned with *Third-Person Pronoun* in HL7 GHP

Final Recommendation for USCDI v3	Alignment with HL7 (LOINC Code)	Current USCDI v3 Draft
he/him/his/his/himself	H (LA29518-0)	
she/her/her/hers/herself	S (LA29519-8)	
they/them/their/theirs/themself	T (LA29520-6)	
Something else, please specify:	nullFlavor OTH	
Unknown	nullFlavor UNK	

Other options are permissible, such as neopronouns (*ze/hir, ey/em, etc.*) and options such as “use only my name” or “any pronouns”, in addition to the above minimum set. For further recommendations related to pronouns, see [Kronk et al \(2021\)](#).

**B7. Name to Use**

String value, representing the name that a patient uses. For instance, a patient whose given name is “William” may go by “Bill”.

**B8. Care Team Member Name to Use**, aligned with *Name to Use* in HL7 GHP

String value, representing the name the care team member uses. For instance, a care team member whose name is “Dennis Johnson”, may go by “DJ”.

**B9. Care Team Member Third-Person Pronoun, aligned with Third-Person Pronoun in HL7 GHP**

Final Recommendation for USCDI v3	Alignment with HL7 (LOINC Code)	Current USCDI v3 Draft
he/him/his/his/himself	H (LA29518-0)	
she/her/her/hers/herself	S (LA29519-8)	
they/them/their/theirs/themself	T (LA29520-6)	
Something else, please specify:	nullFlavor OTH	
Unknown	nullFlavor UNK	

Other options are permissible, such as neopronouns (ze/hir, ey/em, etc.) and options such as “use only my name” or “any pronouns”, in addition to the above minimum set. For further recommendations related to pronouns, see [Kronk et al \(2021\)](#).

**C1. Sexual Orientation, not present in the HL7 GHP, but provided for sake of completeness**

Final Recommendation for USCDI v3	Current USCDI v3 Draft
Lesbian, gay or homosexual	Lesbian, gay or homosexual
Straight or heterosexual	Straight or heterosexual
Bisexual	Bisexual
Asexual	
Exploring or questioning sexual orientation	
Something else, please specify:	Something else, please describe
	Don’t know
Choose not to disclose	Choose not to disclose
Unknown	

Currently “Don’t know” binds to “nullFlavor UNK”, which is not recommended.

**C2. Intersex Status, not present in the HL7 GHP, but provided for sake of completeness; this is an adaptation of the question used by the intersex advocacy organization InterACT.**

Final Recommendation for USCDI v3	Current USCDI v3 Draft
Intersex	
Non-intersex	
I don’t know	
I do not understand	
Choose not to disclose	
Unknown	