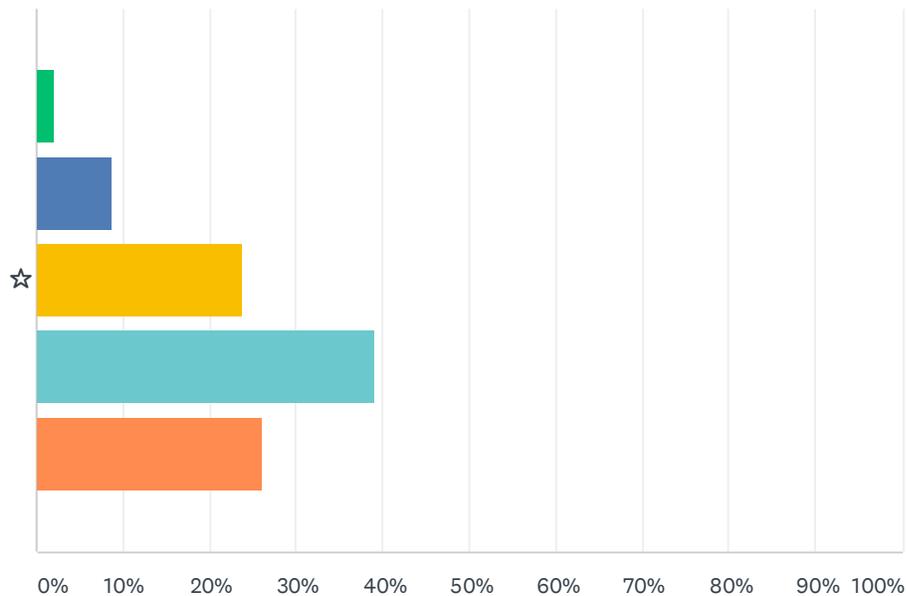


Q1 Is the gender table accurate?

Answered: 46 Skipped: 1

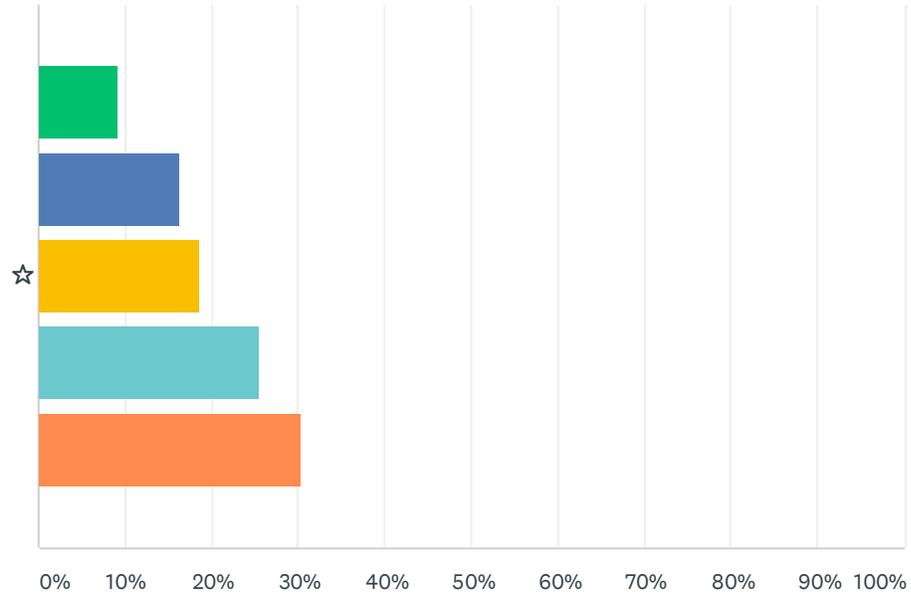


■ Very inaccurate
 ■ Somewhat inaccurate
 ■ Neutral
 ■ Somewhat accurate
■ Very accurate

	VERY INACCURATE	SOMEWHAT INACCURATE	NEUTRAL	SOMEWHAT ACCURATE	VERY ACCURATE	TOTAL	WEIGHTED AVERAGE
☆	2.17% 1	8.70% 4	23.91% 11	39.13% 18	26.09% 12	46	3.78

Q2 Is the gender table list of values complete?

Answered: 43 Skipped: 4



■ Not complete at all
 ■ Somewhat complete
 ■ Neutral
 ■ Mostly complete
 ■ Very complete

	NOT COMPLETE AT ALL	SOMEWHAT COMPLETE	NEUTRAL	MOSTLY COMPLETE	VERY COMPLETE	TOTAL	WEIGHTED AVERAGE
☆	9.30% 4	16.28% 7	18.60% 8	25.58% 11	30.23% 13	43	3.51

Q3 How do you feel about the gender table?

Answered: 34 Skipped: 13

HL7's Gender Harmony Project Feedback Survey

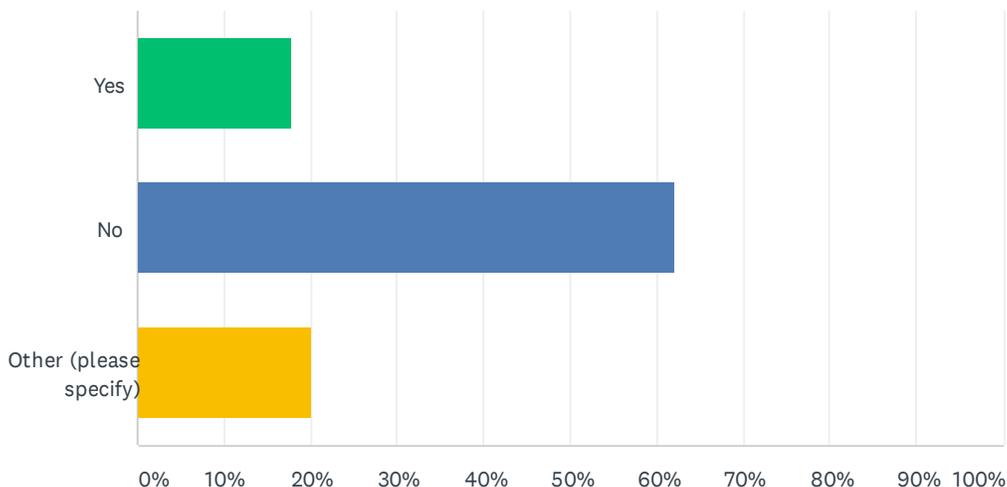
#	RESPONSES	DATE
1	It is appropriate that these set of standard values be updated. My team recently underwent a similar assessment because we found the existing values were insufficient. We arrived at the following recommendation: Standard Values 1. Non-binary (neither solely male nor solely female. Other terms include gender-fluid, gender-nonconforming, genderqueer, gender-creative, or two-spirit) 2. Gender-neutral (identifies as not having a gender. Other terms include agender.) 3. Female 4. Male 5. Other 6. Unknown This would still be an extensible coded value set. We asserted that this would enable a hierarchical coding system for non-binary. Our assumption is that this is the value set for gender identity. We also assessed the need for fields for sex (phenotype) assigned at birth, legally documented sex, and sexual orientation. We additionally did an assessment on if sex karyotype needed to be an additional field but came to the conclusion that this information should already be captured in FHIR Observation elements.	7/13/2020 10:29 AM
2	So many gaps, I don't understand what "See Privacy Note" refers to and also where this list comes from.	7/13/2020 2:44 AM
3	I feel it is too verbose, too many options for the Laman, the 4 at the top is sufficient.	7/12/2020 6:21 PM
4	Too much overlap in the values, resulting in overcomplication. Gender is more diverse now than male/female/indeterminate, but this would be the other extreme.	7/12/2020 5:56 PM
5	Overly complex	7/12/2020 5:45 PM
6	It is descriptive and has most of the genders covered	7/12/2020 4:13 PM
7	Appreciate that it goes beyond Male/Female!	7/1/2020 10:16 AM
8	It shows a greater effort than I am accustomed to seeing to representing the diversity of genders.	6/29/2020 7:26 AM
9	Overall it is great, but still strongly influenced by western concepts and needs more flexibility for people to describe their gendered experience themselves. See comments below.	6/28/2020 1:43 PM
10	A little scared - glad to see this work, but worried about backlash. Overall very thankful you're doing this work and are including more terms than just 'male, female, trans'!	6/26/2020 4:43 PM
11	I think this turned out to be a good set. Having joined a call or two I know it was not easy to work through.	6/26/2020 2:31 PM
12	I think it's a great step in the right direction, although it seems like it's primarily Western terminology, then for some reason with a Native American and a couple of Australian cultural identities. Why two-spirit and not hijra? More specifically, why Aborigine identities and not Māori, Pasifika, or Asian identities? I wholeheartedly agree with being guided by international practices, with the caveat that they should then be adjusted further to fit the local communities.	6/26/2020 2:11 PM
13	Much of this vocabulary will be out of date quite quickly. How do you propose to handle new and revised terms, or terms that become offensive in future?	6/26/2020 1:41 PM
14	seems overly complicated but I understand it is a complicated self-identification problem	6/26/2020 1:31 PM
15	This is a very comprehensive table. I appreciate the additional information provided in the synonyms and description columns.	6/26/2020 1:16 PM
16	Neutral	6/25/2020 10:34 PM
17	Don't feel I know enough to have a final opinion, but the four compulsory values should be well-supported by most of the systems I have seen	6/25/2020 4:16 PM
18	Quite good! I think its accurate and inclusive, and think non-binary is a good choice for the "third gender" option	6/25/2020 9:57 AM
19	Definitions needed for rows 5-n. For example - what does sister-girl mean - Dr. Google wasn't any help. See #6 comment. First 3 rows are solid. I voted neutral because I'm not taking the time to review all the notes and learn why some of the values are in here.	6/24/2020 1:34 PM
20	GREAT - POSITIVE DIRECTION.	6/24/2020 12:49 PM
21	This looks very complete.	6/24/2020 12:17 PM
22	I question how those with multiple identities will be able to indicate that on this scale.	6/24/2020 9:35 AM

HL7's Gender Harmony Project Feedback Survey

23	It is a lot to take in!	6/24/2020 7:39 AM
24	Too many options.	6/24/2020 1:54 AM
25	i like having standard that can be shared	6/23/2020 8:16 PM
26	As a parent filling it out for my child, I guess I would be OK selecting Male / Female according to my child's (trans) gender identity. I'd like to know more about the 'girl' and 'boy' options and what kind of description would be for these.	6/23/2020 7:16 PM
27	It looks good to me, but I am not an expert in this area. I defer to others with greater knowledge.	6/23/2020 4:06 PM
28	positive	6/23/2020 3:11 PM
29	It's still incomplete. While "boy" and "girl" have age to consider, they're pronouns for "male" and "female," resp.	6/23/2020 11:07 AM
30	Overly descriptive - usability limited by too many choices	6/23/2020 10:40 AM
31	Vastly overblown. It seems to me that the categories could be limited to what the patients genetics indicates (male, female, other), and how the patient is to be treated by provider staff, (male, female, other). All the other categories may play some role in a patients psychic economy but of no use to the x-ray tech, the intensivist, or the billing agent.	6/23/2020 8:48 AM
32	The white table has some blanks in synonymous and definitions. Fill them in - https://www.ihs.gov/lgbt/health/twospirit/ Can there be 2 tables. Table 1 just the yellow section and called biological gender and table 2 include PRIVACY/Gender identity. To be respectful of all SOGI members to be identified/not overlooked	6/23/2020 8:28 AM
33	Long list that should be reviewed by a leader in a LGBTQ community group.	6/23/2020 8:02 AM
34	Needs definitions and a hierarchy to be useful. Do not expect most systems to capture this level of granularity.	6/23/2020 7:20 AM

Q4 Should this value set include "Girl" and "Boy"?

Answered: 45 Skipped: 2



ANSWER CHOICES	RESPONSES	
Yes	17.78%	8
No	62.22%	28
Other (please specify)	20.00%	9
TOTAL		45

#	OTHER (PLEASE SPECIFY)	DATE
1	Would need to better understand use cases as to why this is needed as a separate value vs. something that can be derived from a combination of gender and age related fields in a way that can be more flexibly determined by an analytic.	7/13/2020 10:29 AM
2	Transgender (M to F , F to M)	7/12/2020 4:13 PM
3	Yes IF that is current practice for some providers to use those terms to document gender.	6/26/2020 4:43 PM
4	I would not suggest include girl and boy as that introduces the age component which makes those values now convey more than one piece of information. The minimum of the four at the beginning can be used in conjunction with either a date of birth or age data element where needed to derive these two concepts.	6/26/2020 2:31 PM
5	I'm 37 so my opinion is moot. Ask gender-diverse youth, or representative groups like RainbowYOUTH and InsideOut.	6/26/2020 2:11 PM
6	There needs to be a way to manage term sets, including girl and boy.	6/26/2020 1:41 PM
7	Possibly, not sure why they are under consideration - along with sister-girl and brother-boy.	6/24/2020 1:34 PM
8	only if defined clearly by age	6/23/2020 8:16 PM
9	unsure	6/23/2020 3:11 PM

Q5 What data elements would you like to see modified? And How?

Answered: 24 Skipped: 23

HL7's Gender Harmony Project Feedback Survey

#	RESPONSES	DATE
1	For the required data elements, add "gender-neutral" and "other". And potentially add separate values to distinguish between declined and unknown or else clarification on if both situations should map to the "non-disclosed gender" value. Consider a hierarchical coding system for more specific gender identities value classifications that fall under these 6 base categories.	7/13/2020 10:29 AM
2	Needs an introductory paragraph why these terms matter and the importance of allowing choice. Many of these terms are community-specific (e.g. brother-boy, two-spirit). This isn't a bad thing but they aren't as common as others that are missing from this list. Would also consider expanding the yellow sections and recommend the Agency's consults a either HRC or LGBTQI+ stakeholder to discuss definitions before finalising.	7/13/2020 2:44 AM
3	Non-binary gender is not the preferred way of capturing diverse gender expression by the rainbow/LGBTQI+ community. If the purpose of capturing gender is for self-ID then using the category "another gender" with the option to specify is most appropriate. Non-binary gender is still a western concept that erases the experiences of indigenous communities. Here in New Zealand, a country in the South Pacific we have Māori and Pacific people who have their own concepts of gender based on their own cultures. For example, Māori have takatāpui and each Pacific island has unique gender identities which can be remembered using MVPFAFF (mahu, vakasalewalewa, palopa, fa'afafine, akava'ine, fakaleiti/leiti, fakafifine).	6/28/2020 1:43 PM
4	Non-disclosed gender - this either needs to also include that gender reporting is restricted by law or regulation or a separate value for reporting restrictions should be added. I would suggest using them together as the distinction between the two as to why it is not reported is not really relevant to the end user in the use cases I am aware of.	6/26/2020 2:31 PM
5	As mentioned, adjust to the gender identities that are common to Aotearoa.	6/26/2020 2:11 PM
6	This list will just keep expanding indefinitely. What are the processes for mapping constructs and aggregating similar constructs, especially as terms change?	6/26/2020 1:41 PM
7	Electronic records will need to also have a gender listing of "Undifferentiated" (used for neonates with ambiguous genitalia, requiring additional investigation) and "Unknown" (cases when a gender or sex cannot be determined at the time of registration, usually due to patient physical and mental condition). There needs to be a caveat that Unknown or Undifferentiated is NEVER an acceptable substitute for Non-Binary or Non-Disclosed.	6/26/2020 1:16 PM
8	none	6/25/2020 10:34 PM
9	N/A	6/25/2020 4:16 PM
10	I might position agender as the lead term and gender neutral as the synonym. this is based on personal experience in the trans community but not necessarily health care field.	6/25/2020 9:57 AM
11	area for any additional notes.	6/24/2020 12:49 PM
12	n/a	6/24/2020 12:17 PM
13	Maybe be better to allow selection on a 3 or 4 dimensional model of gender. Or at least to ensure multiple selections are acceptable. Agender should be considered for the top section of required included items.	6/24/2020 9:35 AM
14	None	6/24/2020 7:39 AM
15	Many transgender options - possible to use only transgender male/female?	6/24/2020 1:54 AM
16	Some descriptor around how the gender selection is separate and distinct from sex characteristics (physical anatomy)	6/23/2020 7:16 PM
17	None	6/23/2020 4:06 PM
18	The first column should be renamed "gender identity;" second column should be "pronouns." It'll make the table clearer with the caveat that best practice is to ask a person's pronoun and that their gender identity may not necessarily match with their pronoun.	6/23/2020 11:07 AM
19	Need definitions for all terms. All terms should represent a be meaningfully unique concept.	6/23/2020 10:40 AM
20	transman and transwoman should be two words (trans man / trans woman)	6/23/2020 8:48 AM
21	see comment above	6/23/2020 8:48 AM

HL7's Gender Harmony Project Feedback Survey

22	The two tables mentioned in comment of question 3	6/23/2020 8:28 AM
23	Non-disclosed indicates that the individual had an opportunity to answer and didn't. Also need the more generic concept of "unknown" that doesn't make that implication.	6/23/2020 7:20 AM
24	I am not sure about `Sister-girl`and `Brother-boy` I would like to see use case	6/16/2020 6:50 AM

Q6 What needs improvement? Please mention specific section(s) and/or definition(s)

Answered: 23 Skipped: 24

HL7's Gender Harmony Project Feedback Survey

#	RESPONSES	DATE
1	See comments to 3 and 5.	7/13/2020 10:29 AM
2	These are some more accurate and more expansive definitions. https://www.hrc.org/resources/glossary-of-terms https://lgbtqia.ucdavis.edu/educated/glossary https://www.apa.org/pi/lgbt/resources/sexuality-definitions.pdf	7/13/2020 2:44 AM
3	As a person who sex and gender in Male it is difficult for me to interpret many of the values as they have no provided definition.	7/12/2020 6:21 PM
4	Maybe a separation of sex and gender fields. If not separable, may be relevant to record for transgender people if they'r pre or post operative, as that may have clinical care implications. Removal of things like "two-spirit" which is more a colloquialism, and can be approximated with a more mainstream scientific equivalent. Inclusion of such terms may only serve to murky the waters of what is already a complicated subject.	7/12/2020 5:56 PM
5	While this list of potential gender identifiers contains a good variety of elements, I am wondering about the potential value of tracking this data for a patient. Certainly, there are medically relevant facts about a patient that are related to their gender: whether the patient is on HRT, any relevant surgeries, etc. Additionally, a patient's pronouns and title are related to their gender, and need to be known in order to accurately communicate with and about the patient. However, none of this information can be directly inferred with 100% accuracy simply by knowing how the patient describes their gender. The terminology for gender changes over time and across cultures, so I think it would be useful for this element to allow any text as its value.	6/29/2020 7:26 AM
6	Transgender is not a self-ID gender category, because the majority of trans people will just select the gender category that matches who they are (male/female/another gender). But we do need a way of understanding the size and nature of the transgender population as they experience disproportionately poorer health outcomes than the general population. Transgender should be its own category outside of the self-id gender question. It also does not need to be detailed, it could just be "do you have an experience of being transgender?" yes/no.	6/28/2020 1:43 PM
7	There is no mention of cultural concepts of gender other than Two Spirit. There are many 'third sex' or 'third gender' constructs that have different combinations of sex, gender identity and expression and sexual orientation and activity. There's no way a single gender table will capture all of the possible terminologies, and specific terms become relevant with waves of immigration from different countries.	6/26/2020 1:41 PM
8	all terms without definitions need definitions (i.e., I shouldn't have to Google "sister-girl" to discover it is specific to Australian Aborigines (if that is what it is actually referring to)	6/26/2020 1:31 PM
9	In the definitions, I'd love to see an indication that this is the gender as defined by the patient themselves. I feel that this would make it clearer to readers/users who are naive to these concepts and reduce potential confusion and mis-use of values.	6/26/2020 1:16 PM
10	nothing	6/25/2020 10:34 PM
11	N/A	6/25/2020 4:16 PM
12	very much depending on how this will be used, it might make sense to link trans man and transmasculine together (and the same for trans woman/transfem). These are *definitely* not the same thing, but they are conceptually similar and have somewhat similar clinical implications. not sure what this would look like - possibly transmasculine spectrum (including FtM, trans male, transmasculine). Also implications here of should *all* nonbinary/trans AFAB people select this category? not necessarily	6/25/2020 9:57 AM
13	Include Two-Spirit	6/25/2020 9:33 AM
14	Not sure why one specific value for null flavor/data absent reason (non-disclosed gender) is listed. Is this meant to be asked, didn't answer, or didn't ask? The definition is no gender identify specified which doesn't align with chose not to answer.	6/24/2020 1:34 PM
15	Missing definitions for several of them.	6/24/2020 12:49 PM
16	None	6/24/2020 7:39 AM
17	Some descriptor around how the gender selection is separate and distinct from sex	6/23/2020 7:16 PM

HL7's Gender Harmony Project Feedback Survey

	characteristics (physical anatomy)	
18	Nothing that I know of.	6/23/2020 4:06 PM
19	What I see as the heart of this resource is to be able to promote inclusivity by way of pronoun usage. You should probably limit it to just that. Whether someone is trans or not, their pronoun preference is whatever they deem it to be and the audience should be respectful of that.	6/23/2020 11:07 AM
20	Shouldn't have have both Male and Cisgender male in the same codeset - overlapping concepts.	6/23/2020 10:40 AM
21	For clinical record keeping, vastly too many categories to be useful.	6/23/2020 8:48 AM
22	Leave no blanks so no SOGI member will feel overlooked	6/23/2020 8:28 AM
23	`transfeminine` and `transmasculine` are covered under `transgender male/man` and `transgender female/woman` I think this is a repetition Same for `gender neutral` and `agender`	6/16/2020 6:50 AM

Q7 Other comments and/or suggestions

Answered: 23 Skipped: 24

HL7's Gender Harmony Project Feedback Survey

#	RESPONSES	DATE
1	happy/would like to be involved if needed --> rebecca.bartlett@digitalhealth.gov.au	7/13/2020 2:44 AM
2	While an individual may wish to express their gender in a very specific way, I feel thought has to also be given to the consumers of the value and what it means and how they are to be used. What are the use cases for Gender as opposed to Sex? Are there uses beyond socially acceptable greetings? Good morning Ms/Mr/? Jones. Perhaps patient identification. It is hard to determine the correct granularity without understand the use cases.	7/12/2020 6:21 PM
3	If my feedback is useful and you would like to get in touch for further discussions, my email is kai.loke@digitalhealth.gov.au.	7/12/2020 5:56 PM
4	Clinical information systems should collect two things: Birth Sex: should be simple: male/female and other (for more complex cases) Chosen Gender: should allow for all types they wish to associate themselves with	7/12/2020 5:45 PM
5	Are there proposed data elements specifically for pronouns, title, and other gendered-language information about a person?	6/29/2020 7:26 AM
6	I think we need to think about how gender and sex are captured. Typically we have thought about it as a step as part of a registration process. Working through the Infoway work, it is becoming more clear that this is really part of clinical documentation in a clinical encounter.	6/29/2020 3:50 AM
7	Organisations like Gender Minorities Aotearoa, F'INE, Human Rights Commission, RainbowYOUTH, InsideOut, etc, can advise on Aotearoa-appropriate identities to include.	6/26/2020 2:11 PM
8	I suggest using DDI Lifecycle 3.3 approaches to managing and harmonizing variables across different datasets and timelines (variable lineage, variable concordances).	6/26/2020 1:41 PM
9	Merge some categories to be sufficient but less specific, and/or indicate the taxonomy/ontology (isA) relationships when one concept is a more specific class of another (e.g., what are the child classes of non-binary)	6/26/2020 1:31 PM
10	Thank you for undertaking this important work!	6/26/2020 1:16 PM
11	N/A	6/25/2020 4:16 PM
12	I'm not sure what "persona" means in this context and if the intended users of the table will have a better sense of what that refers to.	6/25/2020 9:57 AM
13	The wording of "something else" in your definition of Gender Identity is very othering. The definition is firmly situated in the gender binary. You give examples from within the binary and then refer to anything outside of that as "something else". I would suggest rewriting to be more inclusive: An individual's personal sense of their own being, i.e. Two-Spirit, woman, non-binary, man, transwoman, etc.	6/25/2020 9:33 AM
14	It would be great to include more stakeholders as Project Harmony participants. Los Angeles LGBT Center was asked to participate in this survey by Allscripts and we would be very interested in joining. www.lalgbtcenter.org glopez@lalgbtcenter.org lkimsey@lalgbtcenter.org	6/24/2020 12:17 PM
15	Would like to see data about how various groups already use these kinds of questions to better assess ideal ways of insuring inclusion.	6/24/2020 9:35 AM
16	If you have male/female you shouldn't need girl/boy	6/24/2020 7:39 AM
17	None	6/23/2020 4:06 PM
18	A table is not sufficient alone. Since I believe I am missing context, it is hard to determine just what the end goal is here. Here is the link to a webpage that I think do a good job at inclusive pronoun use: https://lgbt.uni.edu/pronouns	6/23/2020 11:07 AM
19	Gender is a construct that needs to be coded in context of biological sex. Not sure if all the entries are needed if both fields are developed appropriately. This value set seems to comingle the two concepts.	6/23/2020 10:40 AM
20	"demigender"? Will that make a difference in the mg/kg or medication to be administered? We should not let the sexual politicians dominate the clinical utility of data definitions.	6/23/2020 8:48 AM
21	Thank you for doing this important work	6/23/2020 8:28 AM

HL7's Gender Harmony Project Feedback Survey

22	It seems that privacy notes may be relevant for some of the other codes too? Trans should note that when privacy circumstances dictate, a transperson might be identified with any of the other genders as suits their current identity.	6/23/2020 7:20 AM
23	The table doesn't even follow HL7 guidelines for the creation of a vocabulary or value set. Start there before writing a survey. Question two is problematic and needs to be rewritten. These are the possible answers: Very comprehension Somewhat comprehension Neutral Somewhat comprehension Very comprehension It's a two ended scale, starting at the same end on either side, with phrases that are NOT grammatical, and therefore, somewhat incomprehensible, and definite not comprehensive. The terminology table is missing definitions, especially for key terms like "trans" (yes, it has a note, but it still doesn't have a definition), which generally disregards HL7 content guidelines for standards. In other words, the table is incomplete. The table includes in the "Description" terms that appear as Synonyms elsewhere.	6/23/2020 7:13 AM