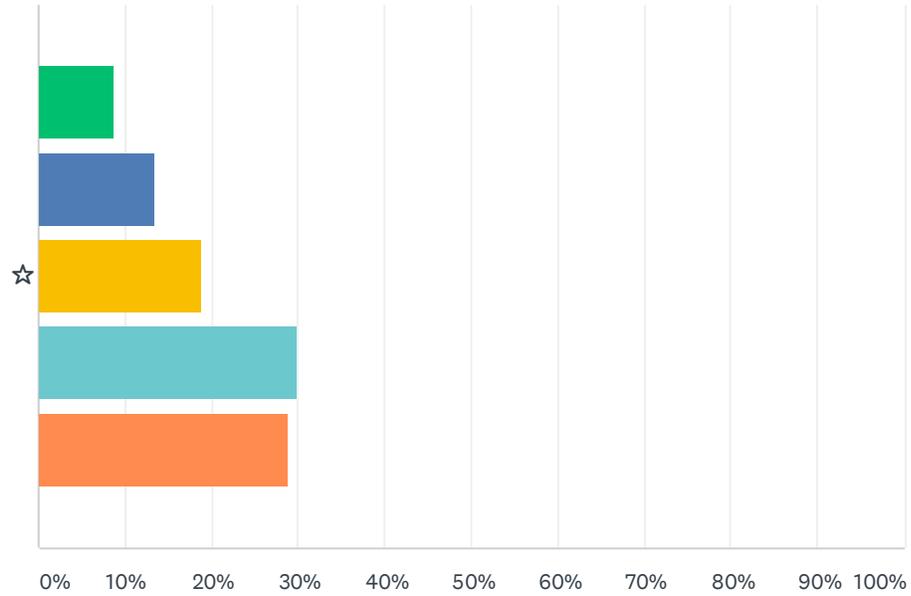


## Q1 Is the gender table accurate?

Answered: 90 Skipped: 3

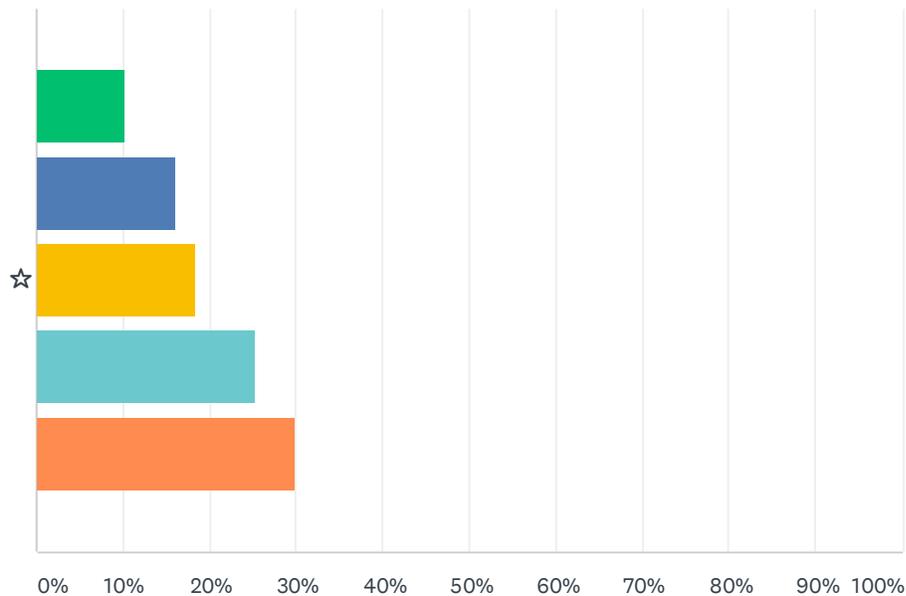


■ Very inaccurate   
 ■ Somewhat inaccurate   
 ■ Neutral  
■ Somewhat accurate   
 ■ Very accurate

	VERY INACCURATE	SOMEWHAT INACCURATE	NEUTRAL	SOMEWHAT ACCURATE	VERY ACCURATE	TOTAL	WEIGHTED AVERAGE
☆	8.89% 8	13.33% 12	18.89% 17	30.00% 27	28.89% 26	90	3.57

## Q2 Is the gender table list of values complete?

Answered: 87 Skipped: 6



■ 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
☆	10.34% 9	16.09% 14	18.39% 16	25.29% 22	29.89% 26	87	3.48

### Q3 How do you feel about the gender table?

Answered: 74 Skipped: 19

## HL7's Gender Harmony Project Feedback Survey

#	RESPONSES	DATE
1	Not great. Gender should not be explicitly included in a medical setting, at least not without explicit context into how it should be used. In a medical setting, there needs to be a distinction between several different contexts: * Linguistic gender and form of address -- how to refer to the person, e.g. which pronouns or linguistic forms to use in non-English languages, which honorific to use (Mr., Ms., Mrs., Miss, Dr., Mx., etc.), whether or not to use Sir/Ma'am and which and which name or names to use in which contexts (e.g. a person who is not out to their family/roommates may use one name on the envelope of a letter and a different name inside the letter). * Legal gender -- in systems that deal with insurance and/or state regulators, the gender in those systems is often important to note. Note that a person may have different legal gender in different jurisdictions (e.g. the genders recognized by state, country, and insurance could be all different) and different documents may have different genders. * Medical information that is often correlated with gender/sex -- This should be listed for the purpose of medical use only and should be treated as confidential medical information. This includes an organ inventory with yes/no marks for each of penis, vagina, vulva, L breast, R breast, uterus, prostate, clitoris, etc. as needed. Also if known may include genetic information (XX, XY, or other), and hormone levels.	9/8/2020 10:33 AM
2	Much better than existing criteria in healthcare	9/8/2020 7:27 AM
3	It's pointless to encode this as a fixed list, and then try to derive other information from that. Instead medical systems should store what they actually need: - the person's title (Ms, Mr, Mx, Dr,...) - pronouns (she, he, they, em,...) - medical information like normal hormone range (like high T/low E or low T/high E) - current body configuration (e.g. does the person have a cervix? -> they should get smear test reminders. This is only loosely connected to gender, e.g. trans men not marked as trans in the system should get those; but cis women with a hysterectomy should not)	9/8/2020 3:35 AM
4	Given the narrowly limited frame of the question, the 4 yellow shaded rows are appropriate, and certainly an improvement on binary M/F.	9/7/2020 5:17 PM
5	Very bad. "male" and "female" must not be used on humans. These terms are for only relevant when breeding, and thus should only be used for livestock, etc.	9/7/2020 3:32 AM
6	I really like the top four overarching set	9/7/2020 2:48 AM
7	think it is an attempt, but a poor attempt, as it lacks sufficient detail for many items. The use of terms is such that even I (a trans man with 40+ years experience working with the trans community understand what you intend, but simply don't understand the way you have constructed items e.g I am a Trans Man not a transman. There is a big difference.	8/20/2020 8:11 PM
8	The conflation of sex and gender is very problematic and an obstacle to safe medical care. Both sex and gender should be recorded for all healthcare records to avoid harming patients and to provide respectful care. The words female and male should only be used to indicate sex (and not in any part of the words used for gender identity). The other words (trans masculine, transman, etc) should be used for gender identity.	8/20/2020 4:03 PM
9	It's fine, but medical records need to maintain both sex and gender categories. Using male lab standards for a transman can lead to a delayed diagnosis of renal failure, for example.	8/20/2020 3:47 PM
10	I feel like this is a poorly conceived political move which will put health and safety at risk and strives to re-define clearly understood terms ("male" and "female") to reflect the preference of a subset of the population, making language fail in its purpose of communication.	8/20/2020 12:05 PM
11	Comprehensive	8/20/2020 3:53 AM
12	Looks pretty good, I like it	8/20/2020 1:52 AM
13	Confused - given the notes about jurisdiction and the disclosure concerns, it seems that male, female, non-binary or non-disclosed should cover everyone and all other descriptions can be folded into these.	8/19/2020 8:10 PM
14	seems to cover a lot - some of the terms are not used in my community but it is good to include as many as possible..	8/19/2020 5:49 PM
15	seems pretty comprehensive; this is an area where terms are evolving quickly	8/19/2020 1:14 PM
16	good	8/19/2020 12:16 PM

## HL7's Gender Harmony Project Feedback Survey

17	It would be helpful to have definitions for all gender descriptions	8/17/2020 8:40 AM
18	Strip it back as technology will not keep up resulting in a data mess. All systems still have MALE/FEMALE. I suggest re-label that to "Born Gender" and then allow a drop down for a new field "Identifies as Gender" as it can be easily amended.	8/11/2020 12:29 PM
19	An awesome job - a huge improvement. I am fully up to date on all the language so only gave a mostly complete as I cannot confirm the listing is very complete.	8/11/2020 4:43 AM
20	I feel it captures the needs of the patient. However, are there some definitions that may be missing from a cultural perspective such as two-spirit?	8/10/2020 9:52 AM
21	It is sufficient	8/9/2020 8:06 AM
22	indifferent	8/7/2020 10:44 AM
23	We have an ever changing world so I think it is important to put in an other so no group is left out.	8/7/2020 9:07 AM
24	I feel that male and female are confusing. When I'm asked male or female I think they're asking about my assigned sex, which may not align with my gender identity.	7/29/2020 7:13 AM
25	It includes many concepts not defined. Do we have the use cases for them from the stakeholder community? Is this data considered administrative or clinical?	7/29/2020 6:32 AM
26	Too many definitions! This will lead to ambiguity and mis-classification unless there is very clear guidance. Further, those systems that do not the full set will have to map the unsupported definitions to the mandatory or minimum dataset and this will be unidirectional. In bi-directionally integrated systems this could also result in loss of fidelity and accuracy. Any definition that relies upon other data/metadata (such as age) should be avoided; these are rarely durable and may introduce unintended consequence (e.g. legal). I see real problems where this relates to concept definitions such as 'boy' and 'girl'.	7/27/2020 8:57 AM
27	While it is a step in the right direction, there are several oversights including a case of significant discrimination.	7/24/2020 5:08 PM
28	It's a good start.	7/23/2020 8:59 PM
29	Appalling. Way too many terms	7/22/2020 11:31 PM
30	Overly complicated. Male, female, other should be the only values.	7/22/2020 10:40 PM
31	I think broader collaboration with the LGBTI community is required to refine Gender values and descriptions. People may identify as multiple of the above. Do not use "something else" - Other would be more appropriate.	7/20/2020 7:08 PM
32	A table like this will never be complete because there are infinite ways to express gender. I wonder if it is necessary to even categorize someone as man, woman, other etc.? It may be more efficient to learn the person's pronouns and any relevant medical information (male, female, intersex, transitioning), as there are so many words a person could use to describe their gender.	7/17/2020 7:06 AM
33	I feel that it is well overdue, however I am concerned about accidental breaches of privacy, and I am concerned about application: natal (or chromosomal) sex may be as important in some cases as the patient's gender.	7/16/2020 8:35 PM
34	good but there needs to be a clear distinction between birth sex and gender with different decision support and value ranges	7/15/2020 11:00 PM
35	More detail than I know what do do with	7/14/2020 6:39 PM
36	I dont have expertise in this area to give an informed opinion. I am happy to accept the recommendations from the group these decisions involve.	7/14/2020 6:10 PM
37	Fairly simple and complete. No specific changes suggested.	7/14/2020 2:44 PM
38	I think we need to work out some sensitive way to handle the gender of people who are undergoing transition from one gender to the other - not covered by the top four choices.	7/13/2020 10:33 PM
39	Concerned that it will add unnecessary complexity to the vast majority of patient identification that is cisgender.	7/13/2020 8:03 PM

## HL7's Gender Harmony Project Feedback Survey

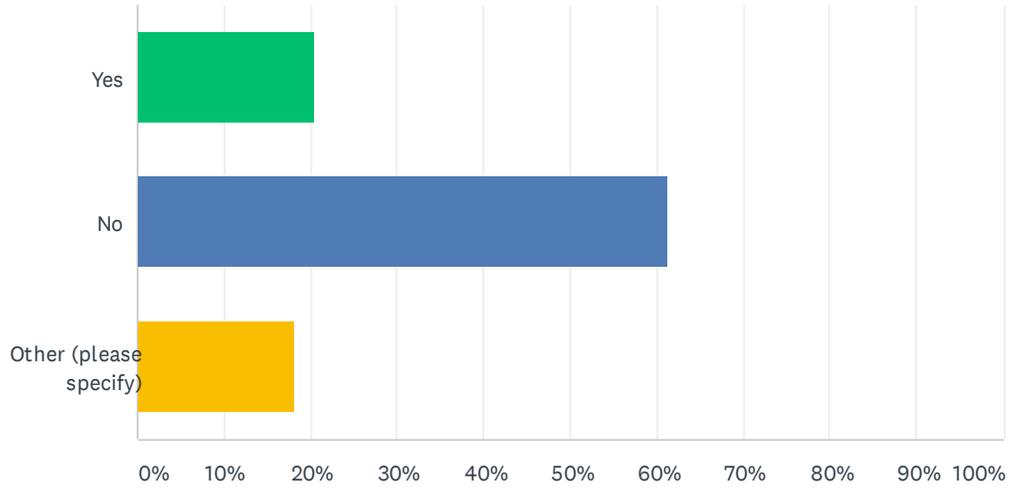
40	This is a social and individual construct. Terminology is also power. Creating new gender terms is often about creating or retaining power. All of this to say it is really dynamic and will continue to change. The top four highlighted in yellow will cover the vast majority of people. However the remaining people will say that it is too broad and not specific and will look for some of the terms that occur further down the table.	7/13/2020 7:45 PM
41	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
42	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
43	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
44	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
45	Overly complex	7/12/2020 5:45 PM
46	It is descriptive and has most of the genders covered	7/12/2020 4:13 PM
47	Appreciate that it goes beyond Male/Female!	7/1/2020 10:16 AM
48	It shows a greater effort than I am accustomed to seeing to representing the diversity of genders.	6/29/2020 7:26 AM
49	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
50	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
51	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
52	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
53	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
54	seems overly complicated but I understand it is a complicated self-identification problem	6/26/2020 1:31 PM
55	This is a very comprehensive table. I appreciate the additional information provided in the synonyms and description columns.	6/26/2020 1:16 PM
56	Neutral	6/25/2020 10:34 PM
57	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
58	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
59	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

## HL7's Gender Harmony Project Feedback Survey

60	GREAT - POSITIVE DIRECTION.	6/24/2020 12:49 PM
61	This looks very complete.	6/24/2020 12:17 PM
62	I question how those with multiple identities will be able to indicate that on this scale.	6/24/2020 9:35 AM
63	It is a lot to take in!	6/24/2020 7:39 AM
64	Too many options.	6/24/2020 1:54 AM
65	i like having standard that can be shared	6/23/2020 8:16 PM
66	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
67	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
68	positive	6/23/2020 3:11 PM
69	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
70	Overly descriptive - usability limited by too many choices	6/23/2020 10:40 AM
71	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
72	The white table has some blanks in synonymous and definitions. Fill them in - <a href="https://www.ihs.gov/lgbt/health/twospirit/">https://www.ihs.gov/lgbt/health/twospirit/</a> 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
73	Long list that should be reviewed by a leader in a LGBTQ community group.	6/23/2020 8:02 AM
74	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: 88 Skipped: 5



ANSWER CHOICES	RESPONSES	
Yes	20.45%	18
No	61.36%	54
Other (please specify)	18.18%	16
<b>TOTAL</b>		<b>88</b>

## HL7's Gender Harmony Project Feedback Survey

#	OTHER (PLEASE SPECIFY)	DATE
1	This value set shouldn't exist at all	9/8/2020 10:33 AM
2	Doesn't matter as long as sex and gender identity are recorded clearly and separately	8/20/2020 12:05 PM
3	these terms are often used with babies and children and people have a very traditional lay understanding...	8/19/2020 5:49 PM
4	not sure	8/19/2020 12:16 PM
5	These two terms need a definition. If girl and boy are meant to be youth versions of female and male, then they should probably not be included unless there are also youth versions of the other genders included. I also feel this may present a problem for registration staff in health care- at what point does some one transition for "boy" to "male"? On the other hand, if they are meant to be youth genders that are used for people who have not yet begun to identify as a specific gender, then they could be included, but needs a definition so their intended use is clear to all.	8/7/2020 8:37 AM
6	OK to include if the age limits are defined.	7/22/2020 11:31 PM
7	This may depend on the whether the definition of boy and girl include parental consent for that identity?.	7/13/2020 8:03 PM
8	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
9	Transgender (M to F , F to M)	7/12/2020 4:13 PM
10	Yes IF that is current practice for some providers to use those terms to document gender.	6/26/2020 4:43 PM
11	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
12	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
13	There needs to be a way to manage term sets, including girl and boy.	6/26/2020 1:41 PM
14	Possibly, not sure why they are under consideration - along with sister-girl and brother-boy.	6/24/2020 1:34 PM
15	only if defined clearly by age	6/23/2020 8:16 PM
16	unsure	6/23/2020 3:11 PM

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

Answered: 48 Skipped: 45

## HL7's Gender Harmony Project Feedback Survey

#	RESPONSES	DATE
1	gender non-conformance is not necessarily related to having a non-binary gender, but can be. E.g. there exist people who consider themselves gender non-conforming cis men. I'm not 100% sure what the table is trying to select for here. In my understanding of how these words are used, it feels like that table entry conflates gender identity with gender expression. I can't with confidence suggest removing GNC from the table, but it's probably better off as not a synonym for non-binary, since that's not universally true.	9/8/2020 1:40 PM
2	Replace the table with several fields storing the actually needed data (like title, pronouns, medical info)	9/8/2020 3:35 AM
3	"trans" and "transgender" are genders and should not be on the list. "non-binary" is also not a gender, its a group of genders.	9/7/2020 3:32 AM
4	I'm unsure about the inclusion of simply "trans" if this is intended as a gender option as as far as I am aware, this is an adjective on top of gender rather than a gender identity in itself	9/7/2020 2:48 AM
5	I do not see male as a synonym to masculine. also the correct word is "Trans Femme" not trans fem. Trans woman is two separate words, same with trans man.	8/21/2020 8:57 PM
6	Now you are asking for an essay - There is an hour's work at least to be done on table so make the table available as a Word or Excel file and I will happily go through it, but not as part of this survey.	8/20/2020 8:11 PM
7	There needs to be section that is for sex and another section for gender identity. Both are important to provide safe and respectful medical care. Words like "transfemale" and "transmale" should be avoided because they mix sex-based words with gender-based words.	8/20/2020 4:03 PM
8	You need to also have a place for sex to be recorded.	8/20/2020 3:47 PM
9	The words "male" and "female" should refer only and always to a person's biological SEX in a health care environment. Gender identity is a separate thing which should have different, clearly defined words. Anything else is dangerous and will lead to poor medical outcomes.	8/20/2020 12:05 PM
10	Girl/Boy only for children.	8/20/2020 3:53 AM
11	As a physician, I would like to know when an individual has "mixed parts" - a trans woman still needs her prostate checked and a tradesman may still need a Pap smear. Long term outcomes of STD, cancers, metabolic states affected by T / E become difficult to track.	8/19/2020 8:10 PM
12	include "cismale/cisman" and "cisfemale/ciswoman"	8/19/2020 1:14 PM
13	As answer 4	8/11/2020 12:29 PM
14	The unsure section? What is the definition - and what about patients who present as an Unknown - do we have a field for that?	8/11/2020 4:43 AM
15	definitions associated next to the descriptions that do not have anything indicate ie.: brother-boy, sister-girl	8/10/2020 9:52 AM
16	none at this time	8/7/2020 10:44 AM
17	More definitions for the gender values on page 2.	8/7/2020 8:37 AM
18	Would like to see definitions and sources. Agender and gender neutral seems to be synonymous. Should only have one uniquely defined.	7/29/2020 6:32 AM
19	1. Swap trans and transgender column entries for consistency with subsequent rows. 2.Except for Gender-Neutral and Gender-Diverse, remove all definitions following cisgender female. These really are synonymous with earlier definitions. Rationale: ambiguous and or duplicate definitions. Compromise: allow non-mandatory sub-classification, subject to integration mapping concerns raised earlier.	7/27/2020 8:57 AM
20	"Transman" and "transwoman" should be omitted entirely, or shifted to include a space between trans and man/woman. The usage of the terminology without a space between the words has become a hallmark of transphobic othering, primarily against transgender women, by drawing a line between "woman" and "transwoman" as though it is a distinct gender rather than simply an adjective modifying a noun. While this is difficult to cite properly, I would point to this blogpost as a place to start (particularly with its reference to Julia Serrano's Whipping	7/24/2020 5:08 PM

## HL7's Gender Harmony Project Feedback Survey

Girl as a more notable work for reference, and also noting the age of the article as evidence to how this is nothing new). <https://takesupspace.wordpress.com/2008/10/15/put-the-goddamn-space-in-transwoman-transfeminism-transmasculine-etc-language-politics-1/>

21	It's "trans man" and "trans woman" not "transman" and "trans woman". Trans is an adjective.	7/23/2020 8:59 PM
22	Only include Male, Female, Unknown. Transgender could be included if the genetic sex is also stated.	7/22/2020 11:31 PM
23	Less elements.	7/22/2020 10:40 PM
24	gender non-conforming is not the same as nonbinary necessarily. A woman can identify as a woman but be gender-nonconforming in the sense that the way she presents herself does not conform to society's expectations. Some nonbinary people might still use it to describe themselves but they are not interchangeable.	7/17/2020 7:06 AM
25	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
26	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
27	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
28	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
29	As mentioned, adjust to the gender identities that are common to Aotearoa.	6/26/2020 2:11 PM
30	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
31	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
32	none	6/25/2020 10:34 PM
33	N/A	6/25/2020 4:16 PM
34	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
35	area for any additional notes.	6/24/2020 12:49 PM
36	n/a	6/24/2020 12:17 PM
37	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
38	None	6/24/2020 7:39 AM
39	Many transgender options - possible to use only transgender male/female?	6/24/2020 1:54 AM

## HL7's Gender Harmony Project Feedback Survey

40	Some descriptor around how the gender selection is separate and distinct from sex characteristics (physical anatomy)	6/23/2020 7:16 PM
41	None	6/23/2020 4:06 PM
42	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
43	Need definitions for all terms. All terms should represent a be meaningfully unique concept.	6/23/2020 10:40 AM
44	transman and transwoman should be two words (trans man / trans woman)	6/23/2020 8:48 AM
45	see comment above	6/23/2020 8:48 AM
46	The two tables mentioned in comment of question 3	6/23/2020 8:28 AM
47	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
48	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: 46 Skipped: 47

## HL7's Gender Harmony Project Feedback Survey

#	RESPONSES	DATE
1	The most important things aren't even asked for in this survey. 1)only ask for what you need, 2)be specific about what it is and why you need it, 3)be self-skeptical any time you're asking trans people to (effectively) misgender/out ourselves, and 4)the one thing you always need to know is our pronouns/how we'd like to be treated, which is social, NOT biological. e.g. if I'm getting a covid test, you don't need to know when my last period was--period. And unless you're participating in research about COVID outcomes, you don't need to know anything about my gender. And if you only ask for assigned sex, not lived or identified sex, it doesn't matter whether you use the right language to say that or not--I won't tell you (unless it's obvious why you need to know) because you're not a safe person for me to divulge that information to. Furthermore, the values may be different based on the reason you need them. If my drivers license and insurance both say "F", asking about my assigned sex will not help you bill my insurance. Asking about my assigned sex might help you know whether to ask about prostate cancer, but it won't help you know whether I need a pap smear--some trans men don't need one, some trans women do. If you're concerned about whether or not I'm pregnant, you need to back off when I tell you that I don't have periods--whether it's because I'm trans or because I've had a hysterectomy.	9/8/2020 10:43 AM
2	When asking gender, context is super important. The answer is dangerously inaccurate when used outside that context.	9/7/2020 3:32 AM
3	There are literally SO many more terms people use, especially those used by communities of color or those from countries other than the US. boi, stud, muxe, hijra, masculine of center, feminine of center, t-girl, t-boy, gender fuck, androgynous, aggressive (AG), butch, femme, gender variant, multi-gender, gender creative, neutrois, kathoey, tomboy, trans, khanith, etc.	8/21/2020 8:57 PM
4	See 5	8/20/2020 8:11 PM
5	The entire table needs to be reformatted and the content needs to be revised.	8/20/2020 4:03 PM
6	See above.	8/20/2020 3:47 PM
7	This is proposed to "improve the standardization of sex and gender data collection and exchange in health care systems" and yet the clear effect of this change would only be to remove any way to track the sex of those recorded. There needs to be a clear, unambiguous way to record the SEX of all patients or clients in a health care environment. This is actually much more important than recording their gender identity. While gender identity is important for patient dignity and comfort, accurate documentation of the SEX of a patient is ESSENTIAL to their health and safety and this information should NEVER be obscured from a health care provider for reasons of "privacy" or any other reason. The SEX of patients and clients must always be accurately recorded for purposes of data collection or such data will be rendered worse than meaningless over time. Gender identity and sex are not the same and this table serves to hopelessly conflate them. Strongly oppose this change.	8/20/2020 12:05 PM
8	Maybe add an "other"-option, because even though this list is very good, i think there will be individuals who define themselves with other terms	8/20/2020 1:52 AM
9	I think I'd want non-binary listed as it's own category	8/19/2020 12:16 PM
10	To reiterate I think all descriptions should be defined	8/17/2020 8:40 AM
11	See answer 4	8/11/2020 12:29 PM
12	as above	8/10/2020 9:52 AM
13	Including "boy" and "girl" for male and female, respectively	8/9/2020 8:06 AM
14	looks fine	8/7/2020 10:44 AM
15	I know some folks use male/female for gender, either b/c they don't see a sex/gender distinction or b/c they really want to assert that their gender is as legitimate as a biological construct. But I still think it's confusing and shouldn't be a highest-level response option. I also find the distinction btw cis fe/male & trans fe/male problematic, as someone's gender identity may be the same regardless of whether they're cis or trans. Cis or trans is more of a "does your gender align with your assigned sex" question than a "what is your gender" question. I'm also, frankly, a little worried about what healthcare systems would do with the granular level of all these options, which in many systems will result in very "small cells" for several of these classes further down the list. Health systems should really only be collecting the data that is	7/29/2020 7:13 AM

## HL7's Gender Harmony Project Feedback Survey

relevant to clinical care or secondary research using clinical data sources. Some of this feels a little like "we just want to know" not "we need to know for a particular reason" and given the risk of clinician bias against trans & intersex people that seems less than ideal.

16	If we cannot fully define the concept, we should not include it. Some resources to better define: <a href="https://www.hrc.org/resources/glossary-of-terms">https://www.hrc.org/resources/glossary-of-terms</a> <a href="https://www.glaad.org/reference/transgender">https://www.glaad.org/reference/transgender</a> <a href="https://www.thetrevorproject.org/trvr_support_center/glossary/#">https://www.thetrevorproject.org/trvr_support_center/glossary/#</a>	7/29/2020 6:32 AM
17	Avoid colloquialism in main definition (allow for these in synonyms). Avoid flat-list style classification beyond a small manageable set. Where entries are included for greater fidelity/accuracy, make these a subcategory of the acceptable broader definition. Systems/data developers and integrators will thank you for this.	7/27/2020 8:57 AM
18	More comprehensive consideration of Nonbinary identities, though I am not a person with authority on this topic to offer that. Though I will say I would be hesitant about inherently connecting gender queer with nonbinary. Including gender non conforming on the table in the same context as the rest also needs reconsideration. Gender nonconforming is a descriptor, not a gender identity in the same sense as the others listed for *most* people who identify as nonconforming, even if it certainly can be a gender identity in its own right. This may actually warrant an additional designation/description that encapsulates the nuance between those terms which are distinctly a gender identity and something that is only sometimes a gender identity.) Lastly, transfeminine and transmasculine should be qualified in the context of trans women and trans men, if not simply removed outright. A trans woman is not inherently trans feminine and a trans feminine person is not inherently a trans woman. The point on the table further down that includes them distinctly is more accurate. To put a fine point on this, a transgender woman who does not transition (ex: for safety) is still a transgender woman even if they do not identify as transfeminine. By placing these as equivalent at all, it may be invalidating for people in scenarios such as that, or even for transgender people who simply wish to maintain the masculinity or femininity associated with their gender assigned at birth.	7/24/2020 5:08 PM
19	Gender nonconforming is not a gender identity and it is not synonymous with nonbinary or genderqueer. Cis men and women and trans men and women can be gender nonconforming. I'm not sure in what context you would need to document that someone is gender nonconforming.	7/23/2020 8:59 PM
20	Remove the vast majority of terms listed. We should not be hijacked by vociferous minority lobbying.	7/22/2020 11:31 PM
21	Some people dislike the creation of a compound word in "transwoman" or "transman" and instead prefer "trans" as a modifier: "trans woman" or "trans man"	7/17/2020 7:06 AM
22	must be national	7/15/2020 11:00 PM
23	The sister - girl, brother - boy definition will be very complex if it depends on the age and gender definition of the sibling. Do we also need to define sister- girl vs sister-transwoman vs sister-transgirl?	7/13/2020 8:03 PM
24	See comments to 3 and 5.	7/13/2020 10:29 AM
25	These are some more accurate and more expansive definitions. <a href="https://www.hrc.org/resources/glossary-of-terms">https://www.hrc.org/resources/glossary-of-terms</a> <a href="https://lgbtqia.ucdavis.edu/educated/glossary">https://lgbtqia.ucdavis.edu/educated/glossary</a> <a href="https://www.apa.org/pi/lgbt/resources/sexuality-definitions.pdf">https://www.apa.org/pi/lgbt/resources/sexuality-definitions.pdf</a>	7/13/2020 2:44 AM
26	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
27	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
28	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	6/29/2020 7:26 AM

## HL7's Gender Harmony Project Feedback Survey

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.

29	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
30	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
31	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
32	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
33	nothing	6/25/2020 10:34 PM
34	N/A	6/25/2020 4:16 PM
35	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
36	Include Two-Spirit	6/25/2020 9:33 AM
37	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
38	Missing definitions for several of them.	6/24/2020 12:49 PM
39	None	6/24/2020 7:39 AM
40	Some descriptor around how the gender selection is separate and distinct from sex characteristics (physical anatomy)	6/23/2020 7:16 PM
41	Nothing that I know of.	6/23/2020 4:06 PM
42	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
43	Shouldn't have have both Male and Cisgender male in the same codeset - overlapping concepts.	6/23/2020 10:40 AM
44	For clinical record keeping, vastly too many categories to be useful.	6/23/2020 8:48 AM
45	Leave no blanks so no SOGI member will feel overlooked	6/23/2020 8:28 AM
46	`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: 41 Skipped: 52

## HL7's Gender Harmony Project Feedback Survey

#	RESPONSES	DATE
1	<p>Gender should not be explicitly included in a medical setting, at least not without explicit context into how it should be used. In a medical setting, there needs to be a distinction between several different contexts: * Linguistic gender and form of address -- how to refer to the person, e.g. which pronouns or linguistic forms to use in non-English languages, which honorific to use (Mr., Ms., Mrs., Miss, Dr., Mx., etc.), whether or not to use Sir/Ma'am and which and which name or names to use in which contexts (e.g. a person who is not out to their family/roommates may use one name on the envelope of a letter and a different name inside the letter). * Legal gender -- in systems that deal with insurance and/or state regulators, the gender in those systems is often important to note. Note that a person may have different legal gender in different jurisdictions (e.g. the genders recognized by state, country, and insurance could be all different) and different documents may have different genders. * Medical information that is often correlated with gender/sex -- This should be listed for the purpose of medical use only and should be treated as confidential medical information. This includes an organ inventory with yes/no marks for each of penis, vagina, vulva, L breast, R breast, uterus, prostate, clitoris, etc. as needed. Also if known may include genetic information (XX, XY, or other), and hormone levels.</p>	9/8/2020 10:33 AM
2	<p>My immediate reaction to this survey is to question the frame. What is the purpose for collecting this information, and could it be done better? I can think of a few possible reasons: legal/administrative, social, and medical. In some jurisdictions, legal/administrative sex must match the patient's documents such as birth certificate, health insurance records, etc. The 4-row gender table seems reasonable here, and is in fact used by governments in some jurisdictions (Australia is just one example). The social purpose is a combination of gender identity and pronoun usage. The 4-row gender table is also useful here. Additionally, it would seem appropriate to also store a "pronouns" field, ideally as free-text. While most people would use the typical options of he/him, she/her, they/them, etc., being able to support arbitrary neopronouns would support affirmative healthcare experiences for the minority-in-a-minority who use them. For medical purposes, we immediately start hitting edge cases: intersex characteristics, surgeries, and hormonal variations both natural and caused by HRT regimens may all influence clinical decisions, and "sex" is not expressive enough to capture these, even after expanding the typical M/F options to M/F/X/N. I've heard of an "organ inventory" concept which seems to be the right way to handle most of this. (I'm not a medical professional, but the concept came to me via a talk by Marni Panas, who has relevant experience.) That is instead of attempting to capture a "current phenotypic organ clinical sex" field, rather capture a list of which organs the patient has and use that. So: if a patient has a uterus, ask them if they might be pregnant before a PET/CT scan. If the patient doesn't have a uterus, either by birth or due to hysterectomy, no need to ask. In other words, reframe the decision from a complicated issue of sex/gender/identity to a simple binary choice: Does the patient have the relevant organ, or not? This is also beneficial to cisgender people. For example, a cis woman who desperately wanted to carry a child, but had to have a hysterectomy for medical reasons, might reasonably be upset by constant questioning as to her pregnancy status, which this "organ inventory" model prevents. There is presumably an equivalent way to account for hormones, but that's beyond my personal expertise. So in the end, we would ideally have a set of fields similar to the following: * Gender * Pronouns * Legal/administrative sex * Organ inventory * Hormone levels</p>	9/7/2020 5:17 PM
3	<p>Asking for gender is dangerous for a bunch of reasons, especially when it is used to decided what care to give. Instead ask questions that directly correlate with the care. e.g. "What genitals do you have?", "Do you have breast tissue?", etc.</p>	9/7/2020 3:32 AM
4	<p>see 5 my email s.t.whittle@mmu.ac.uk</p>	8/20/2020 8:11 PM
5	<p>There was a case recently where a transman went to a hospital because of abdominal pain. Because none of his records indicated sex (only gender), the physicians did not evaluate him for pregnancy. By the time that his pregnancy was discovered, the baby died. This delay in care that lead to the demise could have been prevented if healthcare records indicated both sex and gender.</p>	8/20/2020 4:03 PM
6	<p>Sex is not gender and to pretend it is will harm trans and gender nonconforming patients. Please reconsider this well-intentioned but dangerous guidance.</p>	8/20/2020 12:05 PM
7	<p>See answer 4</p>	8/11/2020 12:29 PM
8	<p>n/a</p>	8/10/2020 9:52 AM

## HL7's Gender Harmony Project Feedback Survey

9	Use cases for capturing this data is important. Who in the healthcare system captures it? is it considered administrative or clinical data? Would this be part of a clinical (observation) profile or patient profile for example. Also how does this apply to children/pediatric encounters?	7/29/2020 6:32 AM
10	You need to have an option for people who use gender labels that aren't listed in the table. An "Other (please specify):". Trans and nonbinary people create new labels to describe themselves all the time and more labels will be created after this project is finalized. There are a lot of culturally specific gender identities but the only one listed here is twospirit. Do more research on this area. Some cultures are adverse to using Western / English labels.	7/23/2020 8:59 PM
11	It is important to know a patient's genetic sex in many clinical contexts (e.g. when considering the origin of a metastatic adenocarcinoma). Prostate Ca does not occur in females and ovarian Ca does not occur in males. If the genetic sex is not known, misdiagnosis can occur.	7/22/2020 11:31 PM
12	I think in general it would be more helpful to simply get the person's pronouns. The fact that there is an option for nondisclosure indicates that it isn't actually necessary to get the person's exact identity. it's an improvement, for sure! but I don't know that it makes sense in the long run.	7/17/2020 7:06 AM
13	I hope that there will be guidelines on how to apply this table!	7/16/2020 8:35 PM
14	I expect that many terms will be understood by very limited groups: for example, what is the difference between transgender man, brother-boy and transmasculine?	7/14/2020 6:39 PM
15	The proposal is a pragmatic approach to addressing the issue. This is an important initiative.	7/14/2020 6:10 PM
16	This is extremely relevant for transitioning patients on hormone treatment whose doctors may need both male and female reference intervals provided. I don't know how this can be done sensitively. Need to consult the trans community.	7/13/2020 10:33 PM
17	I accept male/female/non-binary and non-disclosed definitions as long as individuals adopting the later identities are made aware that it may complicate the reporting of their pathology tests (eg appropriate reference limits). I would, at this stage, also stop with trans and cis gender definitions, as the other definitions, which are clearly even harder to define, also lead to an exponential increase in relationship (eg sibling) complexities.	7/13/2020 8:03 PM
18	having worked through these issues in my healthcare organization multiple times in the last 5 years. I am much more aware of the dynamism that surrounds the ideas of gender, sex and disclosure. One thing is certain, it will continue to change.	7/13/2020 7:45 PM
19	happy/would like to be involved if needed --> rebecca.bartlett@digitalhealth.gov.au	7/13/2020 2:44 AM
20	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 understanding the use cases.	7/12/2020 6:21 PM
21	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
22	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
23	Are there proposed data elements specifically for pronouns, title, and other gendered-language information about a person?	6/29/2020 7:26 AM
24	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
25	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
26	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
27	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	6/26/2020 1:31 PM

## HL7's Gender Harmony Project Feedback Survey

	(e.g., what are the child classes of non-binary)	
28	Thank you for undertaking this important work!	6/26/2020 1:16 PM
29	N/A	6/25/2020 4:16 PM
30	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
31	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
32	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. <a href="http://www.lalgbtcenter.org">www.lalgbtcenter.org</a> <a href="mailto:glopez@lalgbtcenter.org">glopez@lalgbtcenter.org</a> <a href="mailto:lkimsey@lalgbtcenter.org">lkimsey@lalgbtcenter.org</a>	6/24/2020 12:17 PM
33	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
34	If you have male/female you shouldn't need girl/boy	6/24/2020 7:39 AM
35	None	6/23/2020 4:06 PM
36	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: <a href="https://lgbt.uni.edu/pronouns">https://lgbt.uni.edu/pronouns</a>	6/23/2020 11:07 AM
37	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
38	"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
39	Thank you for doing this important work	6/23/2020 8:28 AM
40	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
41	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