## HEALTH INFORMATION TECHNOLOGY ADVISORY COMMITTEE (HITAC) INTEROPERABILITY STANDARDS WORKGROUP MEETING

February 8, 2022, 10:30 a.m. – 12:00 p.m. ET

VIRTUAL

# Speakers

| Name | Organization | Role |
|------|--------------|------|
| **Steven Lane** | **Sutter Health** | **Co-Chair** |
| **Arien Malec** | **Change Healthcare** | **Co-Chair** |
| Kelly Aldrich | Vanderbilt University School of Nursing | Member |
| Hans Buitendijk | Cerner | Member |
| Thomas Cantilina | Department of Defense | Member |
| Christina Caraballo | HIMSS | Member |
| Grace Cordovano | Enlightening Results | Member |
| Steven Eichner | Texas Department of State Health Services | Member |
| Rajesh Godavarthi | MCG Health, part of the Hearst Health network | Member |
| Adi Gundlapalli | Centers for Disease Control and Prevention | Member |
| Jim Jirjis | HCA Healthcare | Member |
| Kensaku Kawamoto | University of Utah Health | Member |
| Leslie Lenert | Medical University of South Carolina | Member |
| Hung S. Luu | Children's Health | Member |
| David McCallie | Individual | Member |
| Clem McDonald | National Library of Medicine | Member |
| Aaron Miri | Baptist Health | Member |
| Mark Savage | Savage & Savage LLC | Member |
| Michelle Schreiber | Centers for Medicare and Medicaid Services | Member |
| Abby Sears | OCHIN | Member |
| Ram Sriram | National Institute of Standards and Technology | Member |
| Michelle Murray | Office of the National Coordinator for Health Information Technology | Acting Designated Federal Officer |
| Carmela Couderc | Office of the National Coordinator for Health Information Technology | Acting ONC Staff Lead |
| Denise Joseph | Office of the National Coordinator for Health Information Technology | ONC Staff Lead |
| Carol Macumber | Clinical Architecture | Presenter |
| Rob McClure | MD Partners | Presenter |

## Call to Order/Roll Call (00:00:00)

**Michelle Murray**
Hello, everyone, and thank you for joining the Interoperability Standards Workgroup. I am Michelle Murray with ONC, filling in for Mike Berry, who is out on leave today, so we are pleased that you could join us. As a reminder, your feedback is welcomed, which can be typed in the chat feature throughout the meeting. Please remember to address everyone, rather than only the hosts or panelists, in the chat feature. Comments can also be made verbally during the public comment period that is scheduled for the last five minutes of the meeting, 11:55 Eastern Time. So, let's begin with the roll call. First of all, the cochairs. Steven Lane?

**Steven Lane**
Good morning.

**Michelle Murray**
Arien Malec?

**Arien Malec**
Good morning.

**Michelle Murray**
Okay, the rest of the members. Kelly Aldrich?

**Kelly Aldrich**
Hi, everyone.

**Michelle Murray**
Hans Buitendijk? Thomas Cantilina? Christina Caraballo?

**Christina Caraballo**
Good morning.

**Michelle Murray**
Grace Cordovano?

**Grace Cordovano**
Good morning.

**Michelle Murray**
Steve Eichner?

**Steven Eichner**
Good morning.

**Michelle Murray**
Adi Gundlapalli?

**Adi Gundlapalli**
Good morning.

**Michelle Murray**
Raj Godavarthi?

**Rajesh Godavarthi**

Good morning.

**Michelle Murray**
Jim Jirjis? Ken Kawamoto?

**Kensaku Kawamoto**
Good morning.

**Michelle Murray**
Les Lenert? Hung Luu?

**Steven Lane**
We saw Les. Les is on camera.

**Leslie Lenert**
Yeah, good morning.

**Michelle Murray**
I see. David McCallie?

**David McCallie**
Good morning.

**Michelle Murray**
Clem McDonald? Aaron Miri? Mark Savage? Michelle Schreiber?

**Arien Malec**
Mark is here.

**Mark Savage**
Sorry, Mark is here now, off mute.

**Michelle Murray**
Oh, there he is, okay. Abby Sears? Ram Sriram?

**Ram Sriram**
Good morning.

**Michelle Murray**
Anyone else that I did not call or who needs to be recognized today? Okay, thank you, everyone. Now, please join me in welcoming Steven and Arien for their opening remarks.

## Workgroup Work Planning (00:02:11)

**Steven Lane**
Well, thank you, everyone, again, for your time and attention and making the effort to come and join us today. You can see the agenda here. We are going to spend just a few minutes talking about where we are in our workgroup process, and then we have two presenters coming to speak to us about the HL7 Gender Harmony Project, which was specifically called out by ONC in their publication of the draft V.3 as an area that they wanted input on to see whether it made sense for us to evolve some of the standards in earlier versions of USCDI to incorporate the work of Gender Harmony, so we are looking forward to that.

We will then have some time to dive back into our Charge 1A, looking at the new data classes and elements that have been proposed for inclusion in the draft USCDI V.3, and we have seen in the Google docs that a

number of folks have started to provide some input there, so I hope that you will be prepared to speak to your comments there, and we will use that as a guide for that discussion. And then, as always, we will have public comment before the end. Hopefully, members of the public who are joining us will feel free to utilize that opportunity to share any thoughts that they have over and above what they might want to put into the chat. So, that is our plan for today. Arien, do you want to add anything before we move on?

### Arien Malec
Nope, seems pretty clear. Let's get into it.

### Steven Lane
All right, and I see that Hans has joined us, just for the minutes, as well as Michelle, so, thank you all for that. Good, all right. So, let's go to the next slide, and another. There we go. So, this is our charge. It is always good to reorient ourselves at the beginning. We have these two charges. Charge 1, to look at the draft USCDI V.3 as published by ONC and provide recommendations regarding the new data classes and elements that were proposed, any adjustments, modifications, clarifications, deletions, etc., and then, once we manage that work over this month, we will look at Level 2 data classes and elements that were judged by ONC to be ready for potential inclusion in a version of USCDI from a technical and adoption perspective, but that were not proposed for draft V.3 and see if there are others that should be promoted or that we would recommend promotion. So, that is what we are going to do here in February and March. We are going to try to wrap up this work by the end of March so that we can present our recommendations to HITAC in mid-April.

And then, come April, we will turn our focus to our second charge, which is going to be looking at opportunities to update the standards in the ISA, and we will look at that during April and May so that we can wrap that up and present our recommendations by June to the HITAC. If there are other works that we feel compelled to address here within the workgroup, we will work with ONC and HITAC leaders to see if there is any additional work for our group to do, but if not, we will have our work wrapped up before the 4th of July. What is on the next slide? I am only working on one screen today, so I am a little hampered. Okay, good, let's back it up then.

So, in your homework, all of you were sent links to two Google docs, which I hope you have had a chance to access. One of them is Member Recommendations, which is a fully editable doc where we have invited each of you to add information related to data classes and data elements that you feel may warrant some adjustment from the draft V.3, and Grace took the opportunity to put some information in there, and Mark did as well, and we invite others to do so also. What we are going to do is use those comments as an agenda as we go through this.

And then, the second document, which I had up, but I lost… Actually, if it would be great if you guys had those at the ready so we could cut over to them on the Zoom if possible. The second one is a document that the ONC had been preparing prior to our meeting. It is called Draft USCDI V.3 Data Elements for ISWG Review, and here, this is where we had captured the applicable standards that apply to each of the data classes and elements that have been proposed in the draft V.3, as well as some notes. So, this digs a little deeper into each of the items, and we will use this. You will see that Al and the team set this up with some additional columns in it. Let me see. Are you guys showing that in the Zoom yet? I am trying to get back and forth. You are? Wonderful. Sorry, no. So, whoever is running the Zoom, can you guys cut over to the Google docs? Is that possible?

### Michelle Murray
Yup.

### Steven Lane
Yeah. So, this was the first one that I mentioned, where we had been collecting detailed input from members. And then, can you cut to the second one? Okay, and this is the one I was starting to talk about, where each of the draft V.3 data classes and elements are listed with some notes from ONC, how they

have been approaching this, the applicable standards as listed in the draft V.3, and then there are these additional columns added to the right.

Now, last year, Hans and other members of our taskforce did the heavy lifting to help us identify which of the proposed data elements was already represented in a FHIR implementation guide and what the state of evolution of that work was, as well as within CDA, and it would be wonderful if Hans and/or others had the time to do that, or anybody, in fact, who is deeply familiar with the HL7 work in this area. It was very helpful for us to know because it led to us identifying gaps. We then met with HL7, and they agreed to close those gaps, and that has become a part of the process, as you heard last time.

So, this is a document that I believe we are providing comment access for the workgroup members. Can someone from ONC clarify that? I think workgroup members can add cell-level comments to this, but not actually edit it. That was our plan, anyway, so people should check that out, but I think we are going to use this to collect additional information as we go along. Any questions about the two documents that we have put up and made available, or has anyone been having trouble accessing them? Okay, good. Katie clarified that members have comment access to the second document and full edit access to the first.

**Arien Malec**
And, thank you, Hans, for starting the review.

**Hans Buitendijk**
You are welcome.

**Steven Lane**
Absolutely. And, for anyone willing to work with Hans on that, you will find Hans is a true delight, so I would recommend it to anyone who has an interest.

**Hans Buitendijk**
As Ricky and I found out, having different interpretations helps figure out what is actually happening.

**Steven Lane**
Absolutely.

**Hans Buitendijk**
It is good to have multiple eyes on it.

**Steven Lane**
Okay. Arien, do you want to add to that in terms of workgroup planning?

**Arien Malec**
No, I am good. I think we have a good plan.

**Steven Lane**
All right. Any questions from anyone? I do not see any raised hands. I am not sure I am looking in the right place to see them.

**Arien Malec**
They show up nicely in the Zoom when people do raise their hands, so it is pretty obvious.

**Steven Lane**
I am trying to do this on a laptop, and there are just way too many windows open here. Good. Well, in that case, Carol and company, would you guys like to introduce yourselves? We will switch over back to your slides.

**Arien Malec**

Steven, let me facilitate this section, and then, you can facilitate the 1A charge. So, thanks to Rob and Carol for presenting on Gender Harmony. I am just going to give a little bit of a background in this topic and this topic area. The HIT Standards Committee, back in the day, made recommendations that we expand our definition of administrative sex and/or gender to be more inclusive and capture both more of the biological variety and the gender self-identity variety that was available as a way of A). Providing better care, and B). Providing better engagement and delivering a more caring healthcare system.

I think at the time, we pointed to the emerging vocabulary quasi-standard that Facebook and other social media platforms had put out. I know that Facebook is not always the best model, in many cases, for representing some of these concepts, but they at least had had a vocabulary, and we were starting to see the emergence of a reasonable vocabulary. Since that time, we have made a huge amount of progress, and so, we have invited the Gender Harmony Project here to talk to us about some of the progress that has been made. This is all related to, as Steven said, our charge for this workgroup, and we should be looking at the presentation here as source material for USCDI V.3. I think there are a number of secondary discussion concepts relating to, with the workflows are in EHRs, how we transition from a primarily administrative concept to a better vocabulary system, and I know that Rob and Carol will have a ton to say about both of those subjects. So, with that, let's turn it over to Rob and Carol. Thank you.

## HL7 Gender Harmony Project (00:14:32)

**Carol Macumber**

Great, thank you so much. My name is Carol Macumber. I am the co-lead of the HL7 Gender Harmony Project. I am, from an HL7 perspective, a cochair of the Terminology Services Management Group, a cochair of the Vocabulary Workgroup, and I lead a sub-taskforce for HL7 external terminology engagement and management via the HL7 Terminology Authority. In my copious spare time, my day job, I am the EVP of Client Services for Clinical Architecture. I am joined today by my colleague Rob McClure. I am going to let him introduce himself this time here. Rob?

**Rob McClure**

That means I have to unmute. So, I am a physician informaticist. I have been involved in the field for quite some time. I focus on terminology, to some degree like Carol, and like her, I am involved in a number of leadership roles at HL7, including vocab. I am the lead in this project and look forward to explaining exactly what the project is proposing.

**Carol Macumber**

Great, thanks, Rob. We can go on to the next slide. So, we include this very simple, in comparison to many of the use cases that we have documented as part of the Gender Harmony Project, to, in a single slide, capture how it is not as straightforward as one may think. In this use case, we have a female-to-male transgender patient presenting for imaging and admit who is anatomically male, but undergoing hormone transition. Their gender identity is male, and present as such as admitting. Their sex for imaging use is female. Their sex for labs is male, or could be more complicated depending on what you are looking to be testing, and their sex for clinical devices and things like an OR setup could be female. Really, just highlighting that the concepts that we have grown accustomed to, such as birth sex, administrative sex, and gender identity are not consistently used or understood. Next slide.

So, just a little bit of background, and I will say we are going to fly through this pretty quickly here so we have as much time as possible for questions and discussion afterwards. The background on the vocabulary working group project known as Gender Harmony began in the spring of 2019, and that was kind of born from a desire just to improve the way we capture sex and gender identity information and a longstanding issue of conflating the use of those two things as interchangeable, and post a specific request from the CDC to improve the administrative gender value set to include a code for nonbinary as it started to begin to be allowed at the state level. It was balloted as an informative HL7 specification in January of 2021 and

published in August of 2021. We describe a logic model for sex and gender identity data representation, which Rob is going to jump into in detail here after I am done.

We meet on at least a weekly basis at 4:00 Eastern, and we have provided a link there to the conference site, which you have probably already seen. We are extremely proud, lucky, and grateful for the wide participation from a number of people and places, including those that are listed here, external SDOs like DICOM and NCPDP. We have had participation at a government level from the U.S., the Canadian government, and Australian government, very importantly, community members from the LGBTQIA+ community, EHR participation from Epic and Allscripts, and the AMA, ACP, ACLA, and others. We have listed here a bunch of use cases which have been derived from that direct participation as the things that they are seeing, implementations, and in guidance that have gaps with regards to sex and gender, and we encourage anybody who has the time and interest to review those use cases, and there is a way in a template for you to add others.

We have just recently published an article in *JAMIA*, which we have also created a link for there, and really, this is our call to action in terms of the time has come, and doing research across the space, we come across many, many instances of supportive research from other bodies to move this ball forward in terms of better representation and exchange of this information. One particular one that we mentioned here is from the U.S. Preventative Services Taskforce. They make evidence-based recommendations on clinical preventive services, and they have recently published their revised approach to addressing sex and gender. They state in that article that disparities in preventive care, such as cancer screening, have been demonstrated for transgender and gender-nonconforming people.

For example, the USPSTF recommendation statement for breast cancer screenings states that, "Applies to women age 40 years or older." However, it is unclear how or whether it applies to transgender, gender-nonbinary, or gender-nonconforming persons, assigned female sex at birth, or intersex individuals with breasts. They are committed to promoting health equity for diverse populations, including based on sex and gender, and ensuring both the specificity and inclusivity of its recommendations. Therefore, they are attempting to advance their methods and language in every step of its recommendation development process. The Gender Harmony logical model and the forthcoming cross-paradigm implementation guidance that we are currently working on can support the clear and consistent USPSTF recommendations by distinguishing between sex recorded for administrative purposes, such as birth sex, insurance coverage, etc., and sex based on clinical observations and gender identity. Next slide, please.

To that end, we provide here a very quick look at the outline of the informative specification that includes a background, current state overview, which is now a little bit old here as we are in 2022, and it was balloted in January 2021, but a lot of it still does apply, and impact on clinical care, on the use of sex and gender, and things like quality measurement, reporting, in payment for payer, and data analysis. There is also a detailed description of the model, including some initial implementation guidance. Again, we are going to be working on improving that and working on improving each of the HL7 product families to provide specific guidance, for example, how you represent sex and gender based upon the Gender Harmony logical model in things like FHIR and V.2, and it includes appendices that had our initial thoughts on the terminology to support the logical model, which Rob will be jumping into next. So, with that, Rob, the floor is yours.

### Rob McClure
All right, I will get unmuted and get to the video. Apologies for those of you desiring to be in a warm place near the ocean, because that is where I am at. I am actually on holiday, so you will hear it here in the background. A lot of the middle part of this slide deck we are going to have to just go through very quickly because I want to get to the last couple of slides, which are the specific questions about essentially how to apply our model to sex assigned at birth and gender identity. But, this is the model. This is the model as described in that informative document. It is also discussed in the *JAMIA* article that is referenced in the slide back before this one. Go ahead. We are not going to get into the details on this, but let me just breeze through the rest couple of slides, so, go right ahead.

These next slides basically describe key aspects with regard to the use of these different elements, and we will come back to all of these in the context of the questions that you have asked. So, I do not think we need to spend a lot of time on this. I would rather spend time on those particular questions, so, next slide. We will just go through these quickly. Those were the first two, gender identity and sex for clinical use, which we will reference in this and come back and talk more about later. Recorded sex and gender is something that we will talk about in the context of how it is used to represent sex assigned at birth, so we can go ahead and move past this one.

The other two elements in the model that we talk about that we will not spend much time on today are very important in the context of interacting with patients, and that is obviously important when they change from the presumption or over the course of time, and that is name to use and pronouns, so they are a part of our model because of how important they are in the context of interacting with patients. Next slide. Again, I do not want to spend a ton of time on these proposed minimum sets. It has come up, and we will talk about it in the context of gender identity about how to interpret what we mean by saying "minimum value set," and that means that we would expect a model that uses the Gender Harmony as its basis, which, remember, is a logical model. They would propose to include a set of codes that are associated with these elements that, at a minimum, have these value sets. In some cases, not gender identity specifically, it would be expected that you would have more, and we will talk about that in a minute.

And then, sex for clinical use is actually the one element where we would propose that the approach is to restrict the set of allowed values to only those included. Again, we can talk about sex for clinical use. It is not part of the questions that we were asked to comment on. I will say it now and I will say it again that I think it would be very valuable for sex for clinical use to be something that is included as a part of the USCDI. It is a break from the way we have thought about things in the past, i.e., we have tended to use sex assigned at birth as a proxy for what we are calling sex for clinical use, and we think that is wrong. Next slide.

Recorded sex and gender: Again, I do not want to spend a ton of time here, so let's go ahead and move on. This speaks to where we stand right now in our project, which is that our first phase was to create that logical model and do the ballot, which we have done. We are now working on Phase 2 of the project, which is to take that logical model and apply it specifically to at least the three main product families at HL7, which are V.2, the CDA- or B3-based elements that create the primary focus of implementers of HL7, and that CDA base, which is C-CDA in the U.S., which actually is referenced by a lot of international organizations, so we are focused on describing that, and then, FHIR.

And, what this means is we are going to publish what is called a cross-paradigm FHIR IG ballot where we will speak to how each of those product families should change to align with the approach that we are outlining in our logical model. So, we have actually begun with V.2. We are farther along with V.2. We do have some draft work on that. We are now actually switching gears and focusing on FHIR because we tend to describe the changes that would align with our approach to be incorporated into the next version of FHIR, which is an important target for everybody, Part 5. That needs to be done in the next month, essentially, so we are working on it very hard. And then, this cross-paradigm FHIR IG ballot will build upon that, and its target for release is September. The RFI ballot will be the next HL7 ballot.

I encourage everyone to come and participate. As noted, we have wide participation, very active participation from a number of other SDOs who are looking to align, so we are a crucible of getting something that everybody can use. It will not be limited to HL7, even though that is what our IG will be specifically targeting, and it will cover a lot of these cases, we hope. All right, next slide. So, this is a slide deck we have used elsewhere, and this was just to clarify that these two things that you have asked us to talk about is our line with the current USCDI, gender identity and recorded sex **[inaudible] [00:29:14]**. Next.

So, this is specific to the questions that we have been asked. Gender identity is in alignment with the idea of gender identity. I wish I could say the way we traditionally think of gender identity is pretty consistent with what we call gender identity. I am not going to go into all of the specifics. I would encourage you to look at

the material in the ballot and the *JAMIA* paper. One of the important things that we state about gender identity is that it is a value, it is a thing that is described by the patient, so individuals who cannot express gender identities so far as the questioner would know do not have a gender identity. You cannot presume a gender identity. You cannot presume a gender identity for an infant, for example.

I have listed on the right side of the slide the USCDI at the top, what is described there, the HL7 Gender Harmony, which was earlier in the slide deck, minimum set, and what ISA says, and this was further discussed, actually, earlier last month at the working group meeting. VA had some concerns, CRS CORE had lodged some concerns because the traditional approach as represented by the ISA and USCDI was to have a whole series of additional genders, which are listed at the bottom there, beyond the minimum set, which is perfectly fine.

So, one of the clarifications was yes, we would expect everyone to be able to say someone is a female, someone is a male. That is their chosen gender identity. They can choose to say something like "nonbinary," and you may need to record "unknown," but, you may choose to do other things, including one of the ones that is No. 2 of the values that have been in the U.S. for quite some time as these transgender-specific values, and there is nothing about what our project is saying that would preclude including those in a particular implementation or jurisdiction, so if the U.S. determined that it is important for consistency, and actually, it is a demand that systems support the ability to say that someone is a female-to-male transgender, then that is something you could certainly do.

The important characteristic here, and I will actually say this was something that became clearer more recently than earlier in the work that we were doing, is we at the Gender Harmony Project are not going to provide any guidance, and in fact, would say there should not be rollups. In other words, you should not presume that that minimum set, female, male, nonbinary, and unknown, that one of the codes that you add, say, female-to-male transgender, should roll up to I do not know what: Male, nonbinary, who knows. That is the problem. If an organization has some constraints that they are working under wherein they have to roll things up, then they are on their own to determine, based on their input to their process, how they are going to do that, but they are not going to get something from us, and I would caution USCDI or the ISA to do something different from what we are doing, which is to say these things, in fact, roll up to something else. Each is distinct.

The other thing is that while there is a list that you see there, it does not include Two Spirit. I think Two Spirit is a very common gender identity that is used in indigenous cultures. I think actually, the meaning is somewhat different. Depending on what culture you are coming from, you may still use that phrase, but it might mean something different. I do not know if that means that it is a problem in using it, and in fact, we have already, through work that… I see Clair has been commenting. Clair and a few other folks who have been active in our project are also very active in Canada Health Infoway. They have been working to improve SNOMED. SNOMED had some issues about its approach to the codes that represent gender identity and sex characterizations, so they have been working to improve those in the context of the Canadian release of SNOMED with the hope that they will then be promoted into the international corps, so you see some examples of this.

All right, I am going to move on. I will let you guys decide if you want to take questions at the end, which is probably best, instead of on gender identity first, so let's go ahead to the other question, which is sex assigned at birth. So, it is important to understand that this idea of sex assigned at birth has some fluidity to it, probably even before we started to try and figure out how we have this one slot sometimes, sometimes two, and it has to meet all of our needs, and so, we are going to tend to try and make changes in that idea as to what it means. In other words, I can change my sex assigned at birth as a way of describing something about what is going on with me. I am not going to speak to whether I think that is the right thing or wrong thing to do, but it is clearly true to us that sex assigned at birth is not gender identity, and it is important to keep distinct whatever the sex assigned at birth might be from gender identity.

In addition, sex assigned at birth, because it has some fluidity associated with it, plus it has other characteristics that make it problematic, it is not equivalent to what we call sex for clinical use, and that probably means we need to spend some time on what we mean by sex for clinical use. We can come to that if we have time, or if you want me to come back and discuss that, but it is not either one of those things, which are 1). The gender identity, or 2). Some summary characterization of clinical observations for a particular use, which is what we oftentimes need a sex characterization for.

So, because of that, because it is neither a gender identity or a sex for clinical use, it is the other thing that we have, which is a wrapper, essentially, the recorded sex or gender, that says, "Hey, there is a sex or gender characterization that is important for a particular context that is neither gender identity or sex for clinical use; therefore, it is important to keep it, and we are going to call it a type of recorded sex or gender."

And, what that means is that for many systems, they have that information in their environment already labeled as, for example, a core element of sex assigned at birth, and they may have a provenance associated with it, it may have come by looking at a document and extracting it from that document, it may have come from a patient just saying, "This is my sex assigned at birth," and what our model would want that to be recorded as the reported sex or gender is the value. The description is "Where did I get that information from?" because I am now communicating it.

Remember, these HL7 models are about communicating information. You can use them as a way of capturing information, but it is really about "Hey, I have this information, I am going to send it someplace else, or I want to tell you about it." And so, this is "I am telling you I have a reported sex or gender. The value fort that happens to be male. I got this out of a patient's EHR record. I got it on this date, today. The period that it is valid that I have about that…" Again, we are probably going to have to make some clarification around this, but the intent was to at least show the date that is on that thing that you are actually describing, so this date would have been February 3rd, and the jurisdiction is for this particular record, and so, in this case, the jurisdiction of this particular set of data is about the patient record jurisdiction, so it is valid in that environment, that jurisdiction is where it applies.

And then, this happens to say, "Well, the thing that we have in our record actually has a LOINC code. It is the sex assigned at birth, and that is our name for the field, 'sex assigned at birth.'" So, that source field name is where we capture what it is that is actually in here because we will also use recorded sex or gender to capture administrative sex, and sometimes it is called administrative gender. It could be sex, as per on my license, or it could be gender, as per a passport, or it could be any other particular thing that would be wrapped with this recorded sex and gender so that it is clear as you exchange it or store it that it is not gender identity and not sex for clinical use. Can you go to the next slide? I do not know where I am.

So, this is kin of the end. This is that link again for our meetings. We encourage people to come and participate. We are working hard to get this IG completed so that we can describe exactly how this is going to apply in FHIR first so that it can get the changes, particularly in patient, but also some associated resources in FHIR for R5, and we will be working to make changes in V.2 and CDA. With that, I will stop, and probably, over time, you have had some questions.

**Arien Malec**
Thank you, Rob and Carol. I am sure there will be a ton of questions, so please raise your hand if you have one. As I have been reviewing the use case information, the very helpful article, and found this presentation to be really clarifying, maybe I can ask the two of you to disambiguate in my head some things that I am thinking about maybe incorrectly. So, I have always understood the distinction between sex and gender to be a biological versus cultural identity, a much more mutable concept. We have a number of places where we assume, implicitly and incorrectly, that the two are the same, that they are immutable, and that they are implicitly binary. Clearly, at a biological level, the biological sex is mostly, but not always, binary, and there is a lot of clinical nuance there.

I guess where I am trying to wrap my head around between sex assigned at birth, which is not quite the biological concept of what and how your chromosomes are configured, the gender identity concept, which I think more naturally fits towards gender identity or self-expression, although I think you are making recommendations that there is a minimum set, and then, how we use these fields, and in particular, the mapping to administrative sex as it legacy exist in our EHRs, in our clinical workflows, in our administrative documents, etc., and then, I start thinking about how we have used that field in particular in patient-matching context, which is the place where I think some of this information is the most sensitive because we make some incorrect assumptions about how we do matching in clinical workflows, in matching systems.

We have a number of places in this country where we assume that sex, which I think we assume in this case is administrative sex, first name, last name, and date of birth, are sufficient fields for driving matching logic. So, I wonder if you can comment on how we go from a pretty static set of concepts that do not terribly well match to either biology or self-expression or identity, how those concepts are currently used in interoperability, and how we think about the transition from one to the other. I know that is a big question in five minutes.

**Rob McClure**
Five minutes, right?

**Arien Malec**
Five minutes, exactly. That is a big question, and that is where my head is spinning right now as I am thinking about making this transition and not breaking the U.S. healthcare system while making the U.S. healthcare system a safer place for people who do not fit neatly into a binary concept.

**Rob McClure**
Right. Well, we all have that goal. So, the answer is that part of this is to not… Our goal was to create a process by which we can transition from the mess that we are in now without forcing us to throw away all the stuff that we currently have, and I think we have done that, and a real key component to that is acknowledging the importance of reported sex and gender as a way of saying, "Okay, this thing is not gender identity, and this thing," again, I think understanding sex for clinical use is really critical to getting the whole picture because most of us came into this thinking, "Oh, okay, sex assigned at birth is sex for clinical use," essentially, and we are saying no, it is not. And so, you have to say, "Well, where am I going to put the right conceptual model that I have around how I know about the presumptions and the documentation of clinical observations that align with a sex characterization," because that is what it is.

Sex is a summary characterization that we have just grown used to doing. There are some folks in our community who would rather we not do that anymore, in fact, so you should not be "setting up" lab results based on the fact that somebody has a particular sex characterization. Instead, you should be aligning the particular test, if it is necessary, to a specific observation that is either known or presumed, and not the fact that they are female or male. Same thing with how you set up the OR. You should be doing that based on observations associated with physiology.

Now, that being said, obviously, that is more work because what people want is to be able to say, "Well, I am just going to look up this code and assume that it is going to give me all the information I want," and most of the times, I am right, and when I am wrong, I will just say I am sorry and move on. Well, we are trying to change that approach, so that is part of what is going on, that you have get consent as a way of saying, "Okay, now we have to go through the process of what we change in order to make that work."

The other thing that I wanted to highlight, again, is through the use of this idea of reported sex and gender, we do not get rid of administrative gender, or administrative sex, or any of these others, and it is funny, but it is very similar to saying the sex that I know is actually reported on a passport, or the gender that is on a passport, or the sex that is here in a particular place. Those are important in the context of some processes that are already baked in, and so, we need to support that, but what we need people to understand is that if you exchange information that is used in that way, it can only be used in that context, and do not go and

grab that administrative sex and do anything other than what you have decided administrative sex is for. I would say that over time, maybe some of those will go away and you will not be using that to do those processes anymore, No. 1.

No. 2, part of what has been a problem is that the administrative sex may be the only thing that is exchanged, and so, people want to use it for everything, including, for example, gender identity. And so, we need to break that cycle so that perhaps the data that might be useful in that particular context, like administrative sex, which is going to be useful for decades, will get cleaner. Did that make sense?

**Arien Malec**
That makes a ton of sense. There was a good set of discussion in the comments which I think I will summarize for understanding, which is the meaning or the intent of sex for clinical use, as far as I have understood and summarized your presentation and the comments, is that sex for clinical use is not even a temporally-bound concept, but a context-bound concept that may, even at the same time, be different in different concepts given clinically what is going on. I think in the use case that you mentioned, I may have laboratory values that are sensitive not to the base biology of what chromosomes a person has or the identity a person identifies with, but more precisely to the hormonal milieu in which that test is being taken. I may have another context where the clinical context is much more tied to anatomy and biology. Do I have that right?

**Rob McClure**
You do. Maybe the person who has the slides can go all the way back to that use case diagram that we had that aligns with that. But, the important characterization about this is that absolutely, our intent is that sex for clinical use can, in fact, support very context-specific exchanges where the system says, "Look, my system is set up so that I have to put an M or an F in, and you need to give me the information that I need in order to be able to set my system up to do that." But, maybe someday in the future, it will not say, "Give me an M or an F." It will be more like, "Give me the result of a particular observation." That actually is what is critical because guess what? There is no system where M or F makes the difference. It is the underlying physiology that is really the issue of interest, but because we have traditionally, as a society, as a species, been using sex characterizations to set up a context for assumptions, we are aligning with that for the time being, and sex for clinical use allows for that. It is basically a restricted set of values that could support sending yes, this particular patient, when you are doing the imaging setup, is a female.

Now, we also support, and actually, it is important to understand that one of the required values for sex for clinical use is "specify," and we took a long time coming up with that phrase. It may be, over time, that we will improve upon what we mean by that phrase, but the phrase basically says there is a specified piece of information, or more than one piece of information, observations about this patient, that you may need to go and look at in order to be able to make a decision as to how to do your clinical decision making that happens to be sex-oriented.

And so, while we do not encourage this because we feel it is outing, No. 1, and it can be misleading, but you could imagine that this patient, at a patient level, would have a sex for clinical use as specified. What that is telling the system is you cannot assume male, you cannot assume female, you need to go and look at observations that are needed for your context in order to make your clinical decision, and so, yeah, we also support, in more sophisticated systems, the ability to tie a particular SFCU to a use, like for imaging, where in that case, it would be proper to send that. Does that help clarify?

**Arien Malec**
That is incredibly helpful. There is a lot of good discussion going on in the chat, but if people want to raise their hand and ask questions, please do. What I am hearing with regard to USCDI V.3 is there is a decision to add gender identity, there is a recommendation from the Gender Harmony group that gender identity should admit at least a four-value code set, where that code set can and should accommodate additional values, and I think the recommendation here is there may be jurisdictional reasons to expand that

vocabulary set, and that we should be wary of adding hierarchical code sets or implying that there is a set of hierarchical code sets that apply.

**Rob McClure**
Yes.

**Arien Malec**
There is a proposal to add sex assigned at birth. I think I heard this team say you could; it is not clear what that gets you, and it may end up driving more complexity than it provides value, and maybe I heard that wrong.

**Rob McClure**
I think what you would hear from us is that we would acknowledge that sex assigned at birth is a piece of data that is captured widely. We would say that the use of sex assigned at birth is so fluid, jurisdictionally driven, and, I think, polluted by the fact that we have not had a good model that covers the breadth of information that we need, that its use is cautious. We are saying yes, only if you truly understand its provenance and how you are planning on using it, and honestly, it is a dangerous item to use.

So, does it belong in USCDI? I actually do not think it does, other than as a comment to a common reported sex and gender kind of thing, just like administrative gender is. Administrative gender is perhaps even more widely implemented. I cannot even tell you what it means. I know what the text that we use to describe it means, I know people very frequently have common use cases, i.e., I want to know what floor to put a patient on in a hospital, but honestly, I am not sure that that is more proper and more properly used than the sort of things that you might be able to do with the sex for clinical use, and yet, it is there, so we are not saying get rid of it, we are just saying be cautious about using it.

**Arien Malec**
Got it, thank you. Are there any other questions for the team?

**Carol Macumber**
I guess just one comment back to your original question about supporting legacy data. Part of this is just ensuring that the data that we are capturing is accurate, and preventing harmful changes to data that has already been taking. In an article or a study that the VA did in, I think, 2019 or 2020, they looked at the fact that that in singular demographic field representing both sex and gender, many transgender/non-gender-conforming veterans chose to change their birth sex information to align with their gender identity. Why? Because this was the only way that they felt heard, that the staff and providers would not misgender them because of the birth sex field in their records, and it would allow them to provide more respectful, gender-consistent pronouns in speaking with them.

However, the effect of this was that changing that birth sex field could cause misalignment with natal-sex-based clinical reminders, medication dosages, and so on. And so, what we are recommending is we need to be much more consistent and separate that information out so that people do not feel the need to go back and change information just so that they can have a respectful interaction with their provider.

**Arien Malec**
That makes a good amount of sense. Mark, you have a question.

**Mark Savage**
Yes. So grateful for this presentation. I just want to make a possible connection with the last discussion on sex assigned at birth. It sounds to me like you are also suggesting that adding sex for clinical use is a way to address some of the difficulties with sex assigned at birth and provides more useful information, so it is an important add to have that, either in addition to or in lieu of sex assigned at birth. Am I understanding correctly?

**Rob McClure**

You are understanding correctly, and again, I would be happy to come back and spend more time talking about what we mean and how we intend sex for clinical use to be used. It is a new idea, but you are exactly right, Mark. The idea here is that you could provide… We are not saying necessarily that you would use sex for clinical use to mean this is the sex assigned at birth, although you can certainly describe, using the model associating with sex for clinical use, the observations that are associated with why, when you saw the patient… I was a pediatrician. I put on birth certificates what I presumed the patient's sex was based on a series of observations. So, it aligns with that if that is really valuable, but think about it for a second. Why is sex assigned at birth even something we characterize and have in our records? It is almost always because we want to be able to make some assumptions clinically with how to treat the patient. And so, yes, it is probably useful somewhere, somehow, but if you start thinking about where it is used, we probably would agree in saying that we would rather systems use sex for clinical use in all those places.

**Arien Malec**

Right. It does not add much over the administrative context where it aligns with documentation and may be used in a matching logic context.

**Rob McClure**

Right. We are very concerned because somewhere, we get missed hits, and outings, and all kinds of discomfort for that community when you run alerts off of sex assigned at birth when what you really should be doing is setting up an SFCU and running them off of those.

**Arien Malec**

Okay. David, you have a question.

**David McCallie**

Yeah, on the sex for clinical use, since it seems so context-dependent, shouldn't it be paired with a context capture as well? How do you know what clinical use it was captured for?

**Rob McClure**

Yeah. Actually, in this slide deck, we do not have all the elements listed out. You would have to go to the big slide if you wanted to show the whole model. This logical model was pretty non-prescriptive with regards to how that stuff would be captured. In the logical model, the place where you would capture context would be comment, but the intent in our translation of this into FHIR, for example, will be to associate it with a context type of link, resource, or something else.

I think we have to assume that there will be places where that will not support, and you will just type in something, but yes, the idea is SFCUs will have a context captured when they are recorded, but remember, by including the "specify" value for the sex value for SFCU, that essentially is true for many patients at a patient level, and it is only there as a flag, and we are really pushing people to say that context is probably associated with particular uses. And so, the idea here is that in those situations where clinical assessments are "sex-dependent," they should be thinking about what are the actual things that we need to know about the patient, and then, looking for those tied to an SFCU if you have the full system up and running.

**Arien Malec**

Yeah. The point seems to be to remind people that there is a context that this should be used for, and it should not be used outside those contexts, and if you do not capture that information or at least give the option of capturing that information, you are going to create just as many downstream problems as we have from our historical mistakes.

**Rob McClure**

Yeah, that is absolutely correct. The only nuance to that is it is not the context that is really critical, because maybe the fact that you have an organ survey associated with an SFCU, and what context would you say that is to be used? It could be in a couple, but there are probably a lot of contexts that that actually applies.

So, what is really critical is I am going to do a clinical assessment, I need to know certain things, and this is the big push change associated with the use of SFCU. We need to get people to start thinking about not just, "Oh, I just do things with females," but "I do these decisions associated with knowing this about a female."

### David McCallie
But, what we ought to be capturing is descriptions of anatomy, and hormone receptor levels, and endocrine levels, etc., if we really want to drive clinical smarts, but I guess that is too far.

### Rob McClure
The point is that this gives us an intermediate step. We can point to F or M associated with an SFCU or specify, but then have a series of… The advantage of SFCU is it supports the idea of pointing the one that is an F and the subset of observations that align with F.

### Arien Malec
Okay. I am going to limit conversation here just in the interests of time, go to Ike, and then, I think we should sum up and go to our workgroup Charge 1A, but, Ike?

### Steven Eichner
Thank you so much. One point to consider is looking at both physical and behavioral health, where behavioral health may have a different definition needed or required, because it is certainly clinical, but there may not be the same set of biological requirements or biological factors.

### Rob McClure
I am not sure I am following that exactly.

### Steven Eichner
Well, if you are looking at sex or gender for clinical use, that may or may not apply to one's gender identity in terms of what care is needed. In other words, I do not know the details, I am not a psychologist or a psychiatrist, I am just pondering whether there is a difference in care delivery in that context.

### Arien Malec
Ike, I think the recommendation here is to add gender identity so that we can provide better care to patients by treating patients with the pronouns and the identity that patients wish to be treated as and make sure that our interactions with people are in alignment with how people wish to be interacted with, so I will let the Gender Harmony team tell me if I have this wrong, but I think that is a clear recommendation to add gender identity to USCDI V.3, to use at least the four-valued code set, and contemplate in it a more jurisdictionally appropriate code set. And then, with regard to sex for clinical use, I think these are emerging concepts that, in our workgroup comment, we should be following closely and make commentary about how we can more align context-sensitive care with the concept of either hormonal and anatomy-specific clinical decision-making or this proxy *n*-valued string that can be potentially used to provide context-sensitive care. Steven, and then we will close this section out and go on to the 1A charge.

### Steven Lane
Yeah, and I think that my comment may be a segue to that. I want to bring us back to the specific ask that came to us from ONC, came to the public from ONC, and that we invited the Gender Harmony team to help us to address, and that was that we were asked to consider realignment of USCDI V.2 data element of sex assigned at birth with that of Gender Harmony's recorded sex or gender. So, that is a question that we want to come up with a response to as a workgroup, and then, that would include the vocabulary or value set and definition, and the second one specifically was regarding gender identity, and to consider realignment of the ONC value set with that of the Gender Harmony Project.

So, I think this has been a very helpful presentation. I have certainly gained a lot from it, but I want to ask workgroup members with regard to those two specific questions that came to us from ONC, does anyone

want to take a stand one way or the other? My personal feeling is that this makes sense. It makes sense to realign the USCDI V.2 data element of sex assigned at birth with Gender Harmony's recorded sex or gender, and I think it makes sense to realign gender identity with the definitions being proposed by Gender Harmony. Does anybody on the workgroup feel differently than that?

**Arien Malec**
With regard to sex assigned at birth, I think we should pass through the V.2 concepts the same warnings that the Gender Harmony team has given to us, which is to make sure when we are recording or defining such concepts that we understand the limitations and the potential benefit, as well as the potential harm that aligning an administrative concept with sex assigned at birth may cause. Mark?

**Mark Savage**
I do not disagree. I think the alignment is good, and I just wanted to add on that my sense is that the Gender Harmony Project has balanced a lot of complexities, jurisdictional differences, cultural changes, language differences, and this is making sense to me as a good starting point to get in a better direction. I see one of the comments about sex for clinical use, and I think that is important for us to keep on the table.

**Arien Malec**
Yes, that feels like it should be a recommendation for future work as opposed to something we know how to implement in context, but it sounds like something that would be a useful add to clinical workflows.

**Steven Lane**
And, it would seem that with the upcoming FHIR IG ballot and, presumably, the opportunity for pilots of the new sex for clinical use data element that that could potentially advance rather quickly through the stages of the ISA process and be ready for future inclusion in USCDI, but unfortunately, it does not seem to be an option today because it has not gone through that process.

**Arien Malec**
Right, exactly. Rob and Carol, unless there are any additional questions on the table, this has been a fantastic presentation. I have personally learned a ton. I know it took a lot of very careful work to get to the point where you are able to deliver clear and crisp recommendations, and I just want to thank you for all the work and thank you for the excellent summary and presentation.

**Carol Macumber**
Thank you.

**Rob McClure**
Thank you. We thank you for the whole team. It is a big group that is working very hard on this project, and as I noted before, if you would like me to come back and spend more time going over SFCU, I would be happy to do that.

**Arien Malec**
Thank you.

**Rob McClure**
And, with that, both of us actually have other tasks, so if you are done with us, we will probably leave you to your work.

**Steven Lane**
Thank you so much.

**Arien Malec**
You are certainly welcome to stay on, but we definitely encourage you to go off to do the valuable work that you do, so, thank you so much. All right, Steven, back over to you.

## Charge 1a Draft USCDI v3 New Data Classes Elements (01:11:37)

**Steven Lane**
Great. Well, thank you all for participating in that discussion, both in the chat and verbally. We clearly ran over with that, but I think it was a good use of our time. Let's go to the next slide. And again, here, just a reminder of where we are in our journey, and I think we have a few minutes before we will shift over to public comment. If we could, within 1A, just to be clear here, they did ask for specific areas of focus, any improvements needed to the data classes or elements, including data classes, names, and definitions, and representative sample value sets, and I know this is a scenario that Clem has a lot of thoughts about, and he is preparing those, and I hope that others will as well. And then, of course, significant barriers to the development, implementation, or use of any of the proposed data elements. So, maybe we could just pop over to the editable Google doc, where the members of the workgroup have had a chance to submit comments, and Grace, I think you were at the top of that document, as I recall. Would you like to make a comment or discuss what it is that you submitted there regarding patient demographics/related person?

**Grace Cordovano**
Sure, let me pull mine up. So, I was looking specifically at related person, and my concern was, as I look at different use cases and circumstances, I felt from the patient and care partner perspective that related person really needs more clarification to ensure that there is no incorrect overlap with care team members. So, the "care team members" field was for anyone that is directly involved in care, whether or not they are a clinician, including primary care partners of patients.

So, when we talk about justification recommendation, are we talking about next of kin and emergency contact, are we talking about healthcare proxy or personal representative? I felt that no matter which way I looked at it, "related person" did not really seem to stand well alone without describing the relationship, and there could be challenges if you do not have that relationship. So, I think "proxy decision-makers" was at comment level, and then, "related persons/relationship" was at Level 2, so I am just wondering what the group's thoughts would be. Is it possible to rename to "next of kin" or require that the relationship is specified to accompany "related person"?

**Steven Lane**
Does anyone want to comment on that?

**Mark Savage**
This is Mark. Just to clarify, I think "related person's relationship" also was in draft V.3 if that helps here.

**Grace Cordovano**
Mark, you are right.

**David McCallie**
Steven, this seemed like a really good suggestion.

**Grace Cordovano**
You are right, Mark. My apologies. I missed it.

**Steven Lane**
No, that is great, and we have all been there, Grace. But, I think that with the inclusion of "related person's relationship," does that satisfy the concern that you are raising? They do seem to be well paired.

**Grace Cordovano**
Yes, absolutely.

**Steven Lane**

Terrific. All right. Well, thanks, Carmela, for jumping in there. I was going to do that, but if you are doing it for us, that is terrific. All right. Well, good. The workgroup decision is we like the fact that they are both included, and we are going to stand by that. We can scroll down. Mark, you were commenting on the same data elements, right?

**Mark Savage**
Yes. In taking a look at it, I was wondering whether there is significant overlap between "related person" and the "care team members." I started looking into that because I was so delighted that "care team members" was added in V.2 and it seemed to be an inclusive term, not just the clinical care team, but all the people involved, community members, family members that would be involved in the care of the individual, and so, I looked at "related person," and it seemed to be a subset of that care team data class. I am guessing that somebody who has thought this through more than I have knows what the distinction is between the two, why this is not an overlap, and why it had something, but I could not see it. I added in the member recommendation column the basic definition of the two, and they really did seem to be similar, so I at least wanted to flag this for a workgroup look.

**Steven Lane**
Thank you, Mark. Hans, you have your hand up.

**Hans Buitendijk**
Yes, and I want to build on Mark's comments and echo part of that. Where in the USCDI it is more encompassing, in FHIR, there is a distinction between "care team" and "related person" that is not necessarily a subset of, but distinct, and I think that may need to be clarified in some discussions as well, so I agree there needs to be some follow-up to make sure that even though the term "care team" is the same in USCDI as in FHIR, actually, there are other concepts in FHIR that tackle part of that, so I think we need to be aware of that and understand if both are implicated as a result, and I am not saying that is wrong, but it is just to be sure there is no confusion there.

**Steven Lane**
I think that is a really good point, Hans, and I do not know whether you or perhaps someone from the ONC team could pull forward the specific definitions that are in FHIR or point us to them directly with a link so that we could review those because it is going to be awkward if USCDI and FHIR are using different terminology to describe these. Just as a response, Mark, I will just say that I think of "care team members" as a subset of "related persons" as opposed to the other way around. There are people related to a patient that are not actually part of the care team that are still worth noting, so I think, again, you could define subsets either way. David, your hand is up.

**David McCallie**
Yeah, just to agree with what you just said, Steven. It seems to me that the confusion is in the definitions of which is more inclusive, "related" or "care team," and like you, I would see care team as a more narrow subset, people that are actively involved in the care, whereas related persons may not be actively involved, but it should be clarified one way or the other.

**Steven Lane**
Great. Grace?

**Grace Cordovano**
I just want to comment. If it helps with context, for example, somebody that has a chronic illness, a life-altering, life-limiting condition will have that care partner, but someone that, say, might be in a motor vehicle accident, generally well, you need a next of kin, so I think that is where the confusion is as to almost the use of that information.

**Steven Lane**

Also, it raises the question of whether there needs to be a defined value set or whether one already exists for "related person." I know when we were working on "care team members" last year, there were some value sets that were referenced, but here, I am not sure if anyone is aware. Hans, thank you for putting those links into the chat. Carmela, if you could just grab those and pop them in the discussion field there, then we will all have them readily available for reference.

**Hans Buitendijk**
Can I just add the binding for "related person's relationships"?

**Steven Lane**
Oh, marvelous. Okay, so we can take a look at those. So, Mark, I think you were saying, "Gee, this seems redundant." Are you still feeling that way based on this discussion, or not?

**Mark Savage**
It is still a question in my mind. I appreciate Hans's point. If I am understanding correctly, the "related person" is an exchange standard, not a terminology standard, but it may explain a part of what is going on. My instinct is that this needs a little further looking before knowing what the appropriate conclusion is.

**Steven Lane**
Well, I would suggest that we take as homework a review of these links that Hans has provided, and come back next time, and revisit this one. And, we have a couple minutes. I know we have a lot to say about disability status. Mark, do you want to kick us off in he few minutes we have before public comment?

**Mark Savage**
Yes, and even if you have read the comments that I put there, it even goes beyond disability status, but I will start there because that was the charge. It got there because the Gravity Project has been looking at exchange standards for source and method of data collection. We have been doing it initially around race and ethnicity, so I provided some detail there. There is a preference for self-reporting, like we have just heard with the presentation from the Gender Harmony Project. But, the source and method and the ability to track changes over time were not a part of the implementation guide at the time, and in my talking with people about EHRs, maybe a deficiency in some EHRs as well where there seems to be, I am told, a default to some observed values, hence our work around race and ethnicity.

But, for purposes of today, it seems like an equally significant question around disability status, functional status, mental function, where there is, as I am talking to experts and trying to get myself educated about this, an equally important preference for self-reporting, so the ability to track that, at least, to know whether one is looking at a value that has been observed or a value that has been self-reported without giving preference to one or the other, but at least to track it so that one knows what one is looking at, strikes me as worth discussion here, and I think I lean toward trying to include that as a piece of the terminology standard. What I did not know is whether my query in the member recommendation is really a part of a provenance data element that gets connected to the disability, etc. data elements or whether it is actually folded into these three data elements.

**Steven Lane**
Thank you, Mark. All right, so, again, we are at time for public comment. We will come back to these items, hopefully next time if we have time, and then, we will also invite you to continue to add to this spreadsheet other items for discussion. Shall we cut to public comment?

## Public Comment (01:24:15)

**Michelle Murray**
Yes. So, if you are on Zoom and would like to make a comment, please use the hand raise function, which is located on the Zoom toolbar at the bottom of your screen. If you are connected by phone only, press *9 to raise your hand. Once called upon, press *6 to mute and unmute your line, and please keep your

comments to three minutes or less. So, I will pause a minute to see if there are any comments. I think I see one.

**Steven Lane**
Oh, good.

**Michelle Murray**
It is Clair's. Clair, if you are on the phone, you can go ahead.

**Clair**
Hi, can you hear me?

**Steven Lane**
Yes.

**Clair Kronk**
That is great. Real quick, this is just one consideration within HL7 and one of the reasons we added the extension functionality to be able to add other things. So, my question revolves around if there are Native American reservations that have specific terminology they would like to use or if, in Hawaii, if they wanted to use "Māhū," or if, in the Northern Mariana Islands, they wanted to use "Palawan" or other indigenous terminologies, will USCDI allow for those to be extended from whatever gender identity set they consider, and if so, have they considered how that might interface with other places that do not have it? Would it be filled in as a string for additional gender identity or something of the sort?

**Steven Lane**
Does anyone feel prepared to respond to Clair's question?

**Arien Malec**
I just wanted to note that the Gender Harmony recommendation was to use the four-valued code set as the minimum code set and be inclusive of the ability send other codes and other coding, and then, in those cases, how responders accept those codes is clearly a thing that we would need to think about from an interoperability perspective, but based on the Gender Harmony recommendations, it feels like the responder should be prepared to handle codes that are not in the code set and maybe remap them to some sensible default as text, but that is going to be an interoperability receiver local decision when they get a code that they do not know how to handle.

**Steven Lane**
It also seems that there is an opportunity to continue to expand the value set as these opportunities are identified. Clair, let me just say thank you so much for joining us today. Your comments in the chat were most helpful. Carmela, you had a comment here, "Not rolling up codes." Okay. Any other public comments in the hopper?

**Michelle Murray**
I do not see any other comments.

**Steven Lane**
Wonderful. Thanks so much, Michelle. So, we are going to be getting together and putting together the formal homework ask, but I think as you have heard, there is some work to be done on determining which of these proposed data elements are covered in US CORE and C-CDA. There is an open invitation for people to submit comments on both of the Google docs, and next week, we will be continuing our focus on patient demographics with a presentation from the Project US@ team at ONC and looking at the question that we have been asked by ONC that the public has been asked as to whether the Project US@ standards should be adopted as part of USCDI. Any questions or comments from the workgroup before we close? Arien, back to you.

**Arien Malec**
Thank you. So, it sounds like we made a ton of progress here. I want to thank the workgroup and, again, re-thank the Gender Harmony team for their presentation.

**Steven Lane**
Mark snuck his hand up there. Do you want to get the last word in, Mark?

**Mark Savage**
That was not my desire.

**Steven Lane**
Oh, okay.

**Mark Savage**
I am sensing from this that we need some precision around distinguishing exchange standards from terminology standards, which is something I am getting myself up to speed on with the Gravity Project work, and I am flagging that for myself for today's discussion, but also going forward.

**Arien Malec**
Thank you.

**Steven Lane**
Thank you. And, thank you all for your time and attention. We will see you next week.

**Adjourn (01:29:02)**