Transcript

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

March 1, 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
Michael Berry	Office of the National Coordinator for Health Information Technology	Designated Federal Officer
Al Taylor	Office of the National Coordinator for Health Information Technology	ONC Staff Lead
Denise Joseph	Office of the National Coordinator for Health Information Technology	ONC Staff Lead
Silvia Yee	Disability Rights Education and Defense Fund	Presenter

Bonnielin Swenor	Johns Hopkins Disability Health Research Center	Presenter
Megan A. Morris	Disability Equity Collaborative	Presenter
Matt Elrod	MaxMD	Presenter
Holly Miller	FHIMSS	Presenter
Terry O'Malley	Individual	Presenter
Alexis Snyder	Individual	Discussant
Michelle Dougherty	RTI International	Discussant

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

Mike Berry
Hello, everyone, and thank you for joining the Interoperability Standards Workgroup. I am Mike Berry. I am with ONC and we are pleased then you can join us today. We have several guest presenters and discussants who have joined our meeting today. We would like to extend our welcome, our appreciation for their participation. As a reminder, your feedback is always welcomed. It can be typed in the chat feature throughout the meeting, or can be made verbally during the public comment period that is scheduled at about 10 until noon Eastern Time this morning. Let us begin roll call of our workgroup members. When I call your name, please indicate your presence. And I will start with our co-chairs. Steven Lane.

Steven Lane
Good morning.

Mike Berry
Arien Malec.

Arien Malec
Good morning.

Mike Berry
Kelly Aldrich.

Kelly Aldrich
Hi, everyone.

Mike Berry
Hans Buitendijk.

Hans Buitendijk
Morning.

Mike Berry
Thomas Cantilina. Christina Caraballo.

Christina Caraballo
Morning.

Mike Berry
Grace Cordovano.

Grace Cordovano
Good morning.

Mike Berry
Steve Eichner.

Steven Eichner
Good morning.

Mike Berry
Sanjeev Tandon who is standing in for Adi Gundlapalli. Sanjeev? Raj Godavarthi.

Raj Godavarthi
Good morning.

Mike Berry
Jim Jirjis.

Jim Jirjis
Good morning.

Mike Berry
Ken Kawamoto

Ken Kawamoto
Morning.

Mike Berry
Leslie Lenert. Hung Luu.

Hung S. Luu
Good morning.

Mike Berry
David McCallie.

David McCallie
Good morning.

Mike Berry
Clem McDonald. Aaron Miri. Mark Savage.

Mark Savage
Good morning.

Mike Berry
Michelle Schreiber.

Michelle Schreiber
Morning.

Mike Berry
Abby Sears. And Ram Sriram.

Ram Sriram
Good morning.

Mike Berry
Good morning to all. Now, please join me in welcoming Steven and Arien for their opening remarks.

Workgroup Work Plan (00:02:17)

Steven Lane
Thank you so much for kicking us off there, Mike. Thank you to all of the folks who joined us as discussants today as well as the members of the public. There are quite a number of folks. I think this is definitely our most popular meeting so far so we are excited to jump right in. If we could go to the next slide, I want to start by jumping into our plan, as it were, how we are going to be approaching this today. Our focus today is on the health status data class, collecting as much information as we possibly can to inform the deliberations of our workgroup to then turn those into specific recommendations back to the HITAC and the ONC for how to optimize this data class in the anticipated Version 3 of the USCDI. Essentially, we have this slide where it was focused on our Task 1A, but we are going to be looking at all these issues today. Ignore the light gray versus the black.

Our tasks here are to evaluate the draft USCDI Version 3 that was published by the ONC and to provide input, both with regard to the new data classes and elements that have been proposed for draft V3, as well as to other data classes and elements that have been determined to be at Level 2 but have not yet made their way into the draft V3. We are suggesting, out of all that has been proposed, what should be included in V3. Should it be more, or less, or different than what was proposed in the draft? Specifically, we are looking for potential opportunities to improve on the data classes and elements that were included in draft V3, looking at how they are named, how they are organized, how they are defined as well as opportunities to suggest representative value sets that may be used by developers and implementers as these are being implemented in the future.

Then, as it says here under number two, are there items within Level 2 which have been determined to be functionally and technologically ready for inclusion in USCDI that perhaps should be included in the final V3 that were not in the draft. Then also, looking for any barriers to the development implementation of these items that might suggest that indeed they might want to wait until a future version. That is where we are at. Our focus today will be on the health status data class, which is a new data class that has been proposed in draft V3. It includes a number of data elements. Al is going to walk us through those. Some of these are data elements that have already been present in prior versions of USCDI that were suggested to be moved into this data class and others are brand new.

I just want to contextualize this a little bit. I think we have a real opportunity today to advance the interoperability of data related to health status and specifically, as we will see, related to disability status, functional status, et cetera. These are very important concepts. As a practicing primary care physician, I can tell you that I often lack this discrete data for patients whom I am caring for when they are being seen by other members of their care team. It would be wonderful to have that information available to be able to coordinate and integrate their care. Similarly, as an individual, I am currently experiencing some functional limitations related to some major orthopedic surgery I had recently and it would be wonderful if my physical therapist, my orthopedist, my primary care physician could share that information to stay up to date on the state of my needs, et cetera.

Again, we have a real opportunity to move this data class forward. We want to do it as mindfully as we can with as much detail and specificity as is possible to reflect the tremendous work that has been done across the community on these data elements. I would caution us to avoid restricting the progress of these data. I think we have seen with USCDI that we can get items into the structure even when they are not 100% specified. The industry is amazing in its ability to go with that opportunity and to advance data elements, whether it is through additional standards, additional value sets, additional use cases, and implementation guides. I think our job here is to see how good we can make this and hopefully keep it moving forward. Arien, do you want to add to that?

Arien Malec
No. I will do that during the panel introduction.

Steven Lane
Wonderful. Al has offered to give us an introduction to the health status data class that was included in USCDI Version 3 to try to put this into context.

Introduction to Health Status Data Class (Draft USCDI v3) (00:07:44)

Al Taylor
Thanks, Steven. Next slide, please. As Steven mentioned, and all the reasons that Steven mentioned, ONC introduced the health status data class as a way to reorganize some of the different data elements in USCDI Version 2 as well as to introduce these new concepts that we were talking about. The new health status data class has, as its definition, a similar definition to a previous data element of health concerns. That health status data class is defined as these health-related matters of interest, importance, or worry. That has a pretty wide range of scope for patients, their family, or their providers.

It includes two existing data elements that came from their own data classes. That is the health concern data element, which is a bit of a legacy data element that goes back to the common clinical data set before USCDI as well as the smoking status that has been part of a requirement of certified health IT going back to at least 2015, if not 2014. These are status check data elements, or a way to express particular concerns. We felt like they fit into more of a broad category of health status. Of the four new data elements that we introduced, one of them was pregnancy status. We have been really wrestling with how best to represent pregnancy status for a long time. We started in earnest during the Zika epidemic. We recognized that it was important to be able to at least evaluate a person's status or potential status for pregnancy, which would shape our approach to caring for that patient in situations where a condition might interfere with or complicate pregnancy or pregnancy might affect the ability to care for a patient with another condition like Zika.

We added pregnancy status. The three that we are mostly going to focus on today are disability status and functional status, which are related, and are maybe two sides of the same coin. They are typically a structured assessment for those areas, whether assessing function or assessing the lack of function or disability. Then, mental function is one aspect of functional status, but it includes evaluations such as cognitive status, structured and unstructured evaluations of one's mental function. In general, we felt that these fit into the category of the health status. We will hear debate about the best way to represent the data elements as well as the data class itself. Particularly related to disability, there has been a lot of feedback that we have gotten from this workgroup already and several stakeholders that are outside the workgroup. This feedback is that disability is only one part. It is a condition that affects a person, but to focus only on the condition that affects the person without addressing how we approach taking care of that patient or person, we have left a little bit of a gap.

Next slide, please. We also want to focus on being able to capture the other side of disability, which is the accommodations. The definition that was submitted as a data element in USCDI and is a decent working definition for accommodations, from a clinical perspective I feel like this can be thought of as a treatment for a disability, or a clinical approach, or a treatment approach to a disability and to provide for a patient that has a disability in order to improve their function or ability to cope with that disability. Grace Cordovano submitted the accommodation data element in USCDI. It was introduced and it was evaluated at a comment level, which means less mature. The reason is evaluated as less mature is because it did not have associated standards or terminology associated with it. Part of that is because the accommodations themselves can be thought of as a significant group of different items. It could be a medication.

I am skipping directions but the middle bullet is the one way to look at accommodations is to look at it as a collection of different things that can be done or provided for a patient in order to address that disability. This could be an order for durable medical equipment, a particular medication to address the disability, a treatment or procedure, or even in a more generic sense a plan of care to provide accommodations to address that disability. That is one of the reasons why it is difficult to put your arms around accommodations because it can be represented in a lot of different ways. That points to one of the ways we can approach accommodations. Do we already capture the essence of accommodations in these other data elements, like orders, like medications, like treatments or procedures? Are we already addressing them with these various USCDI data elements? Do we keep it as a separate data element and then try to put that data element together with all these different data types or other concepts?

I leave that as an open-ended question. We will get into it during our panel discussions. This is one way to look at accommodations for disabilities and possibly signaling how we approach it with recommendations for USCDI data elements. I will turn it back over to Steven or Arien.

Arien Malec
I got it.

Al Taylor
Okay, to move to the next section.

Arien Malec
Let us go to the next section. We have a fantastic set of panels lined up. We could have filled the entire time and more with panelists. This topic has attracted a substantial amount of the passion and interest of the standards oriented and care planning and Disability Rights community. If we can, go to the next slide. As Steven said, this topic of disability status, functional status, and cognitive status, exists on a continuum. All of us are going to experience some form of functional limitation, disability, or cognitive impairment in our lives. As Steven gave a personal reflection, I will give one as well. I personally am immunocompromised secondary to B-cell leukemia for which I received active treatment about this time last year, a B-cell cytotoxic treatment. Despite multiple vaccinations, I do not have a working antibody response. I rock climb outside, but I am very fearful inside. I have substantial limitations to some aspects of daily living.

On the other end of that continuum, my son has tuberous sclerosis, has had seizures since he was five months old, has significant cognitive delay, developmental delay, and continues to struggle with epilepsy. he is going to require full-time care to complete activities of daily living and he is going to require a substantial amount of both medical care and accommodation. I mention this to point out that all of these issues of disability exist on a spectrum. There is no binary on or off related to disability. It is something that all of us will experience. There is a temptation to think that it is a status, that it is an inherent part of a person, but it is temporary. It exists on a continuum and it changes over time.

Also, note that there is a substantial amount of self-identity sometimes attached to these statuses and because they are almost inherently normative or arrayed against some sort of normative baseline, there is a temptation to categorize these statuses as deficits. Because of that, there is a substantial amount of personal identity associated with the documentation of these statuses. Again, just as a personal reflection, how we approach these statuses depends on what aspect of daily living we are talking about. When we are talking about my son and living as happy and productive a life as he possibly can, he is a very joyful individual, we love being around him, but when it comes time to advocate for him in applying for disability benefits with SSA or applying for appropriate accommodations with the school system, you bet that we are going to describe his disability in as clear, accurate, and clinically descriptive terms as we possibly can to justify the appropriate amount of accommodation possible.

With all of that as preface, and also underscoring Steven's notion that we really want to advance the state of the art to better accommodate and better support this continuum that all of us will experience in our lives, and make sure the clinical infrastructure that we have and the interoperability infrastructure we have better accommodates all of our health status. I am pleased to introduce our lead-off presenters. Silvia Yee has been a tireless advocate for Disability Rights as part of the Disability Rights Education and Defense Fund.

As part of that role, Silvia is an advocate for Disability Rights in the school system and in work. Bonnie is an epidemiologist who has been looking actively at how functional status and disability status disproportionately affects, for example, COVID response and health outcomes and is interested in the topic of how we better build systems of care for populations.

Megan has been working on the ground better enabling electronic health record workflows to better document disability and functional status in EHRs as part of her academic work. I cannot think of a better panel to lead off and walk us through these topics and help us formulate recommendations. Sylvia, Bonnie, Megan, over to you.

Presentation (00:21:09)

Bonnielin Swenor
I want to first say thank you so much for sharing your personal perspective. That means an enormous amount. Thank you to the committee for inviting us here to talk about this increasingly important and long overdue topic. I am Bonnielin Swenor, Director of the Johns Hopkins Disability Health Research Center. As was introduced, I am accompanied by Dr. Megan Morris from the University of Colorado Disability Equity Collaborative and Silvia Yee from Disability Rights Education and Defense Fund.

I want to start by recognizing the complexity of this conversation. By design, the disability community includes a broad group of people, as was just described so well. As disability advocates, data scientists, and researchers we are here to help breakdown some of that complexity. There has often an imprecision in the terminology that we use to describe the disability community. Two people can use the word disability to mean two entirely different things. When we are talking about data, we have to first start by being clear about what we are measuring and why we are measuring it.

Next slide. The data elements being discussed today are measuring two constructs of disability: A social or demographic construct and a medical construct. Each can be linked to separate data elements, as shown on the slide. I want to highlight that that social or demographic construct of disability is often conflated with the medical construct. Much like a Venn diagram, these are separate but, at times, can be overlapping domains. Data related to functional and mental status under discussion today fall under the medical construct and are important for clinical decision-making and care planning, but the disability data element assesses the social, demographic, and identity construct that was described, again so well, and is akin to how we collect information on gender identity, race, and ethnicity. Similarly, it is important that this type of disability data be self-reported.

Demographic disability information is needed to identify and address healthcare inequities and improve healthcare outcomes such as quality, safety, and satisfaction for people with disabilities and for closing gaps in healthcare access such as via telehealth. This information is also needed to understand the role of social determinants of health, including transportation, housing, food access, on healthcare outcomes for the disability community, and it can be used to identify patients who might benefit from accommodations during healthcare appointments.

Next slide. Recent national prevalence estimates for my center indicate that over 67 million Americans have a disability, and we actually know that has an underestimate. That equates to more than 26% of our

population or more than one in four adults. What that means is that people with disabilities are the largest minority group in the United States.

Next slide. Despite this high prevalence, people with disabilities face unaddressed health and healthcare disparities. People with physical or cognitive disabilities are more likely to have diabetes and heart disease. People with intellectual and developmental disabilities are six times more likely to die from COVID-19. Women with physical disabilities have lower rates of receiving preventive care with only 54% receiving Pap tests as compared to 83% of women without those types of disabilities. And one in three people with communication disabilities delay their healthcare due to having trouble finding a provider and are three times more likely to experience a preventable adverse medical event.

Next slide. The past two years have only magnified the health inequities that impact the disability community. Our national COVID-19 response has been limited because we do not collect this type of disability information in healthcare encounters and in healthcare settings. Data on race and ethnicity captured in electronic medical records has been critical to shed light on disparities in the pandemic response for those groups. However, the absence of similar disability data has removed the opportunity for us to track COVID-19 infection, vaccination outcomes, care and equipment allocation among people with disabilities. We need this type of disability data to act on health and healthcare inequities that impact more than a quarter of our population.

Next slide. To put it simply, we cannot improve what we do not measure. We must collect disability information along with other demographic data to improve the quality of health in healthcare, to track the effects of interventions aimed at addressing health inequities such as during COVID-19, and to identify people who might benefit from accommodations, including in healthcare settings. The inclusion of disability data in health information systems really cannot wait. I am going to now hand it off to my colleague, Dr. Megan Morris, who will outline evidence and specific recommendations.

Megan A Morris
Thank you, Bonnie. I want to start this discussion talking about what evidence we have for documenting disability status in the EHR. First off, many people have concerns about whether or not people with and without disabilities will be offended by these questions. I can assure you today that is not the case. We have done interviews and focus groups and surveys of patients with and without disabilities and overall, they say they are comfortable with disclosing a disability status and they actually expect their healthcare system to be collecting information about their disability. As evidence of this, in Colorado at UC Health, we did a pilot study in which we rolled out collection of disability status as part of new patient registration in primary care. Over the course of our study period, over 3,000 patients were part of this trial and were asked about their disability status. No patients reported any concerns with being asked about their disability status. We are just not concerned about that issue.

There is a legal requirement to document and record patients' disability status and accommodation needs. We have the Americans with Disabilities Act that states that all healthcare organizations need to provide accessible and equitable healthcare to people with disabilities. The DOJ has released more recent recommendations and standards related to this as part of their barrier free initiative for the healthcare setting. Again, they reiterate all healthcare organizations need to be identifying and providing healthcare

accommodations to patients who need them. To be able to do that, you first need to know who has a disability.

I will pause here. When I am talking about accommodations, I am talking about items in the healthcare setting such as height of adjustable exam tables, such as voice amplification devices, such as large print or braille materials, that again, assist individuals with disabilities to participate to their maximum ability in their healthcare. We had a grant a few years ago and we interviewed a wide range of stakeholders, from policymakers, to advocates, to researchers, to insurance companies, to professional societies. We asked the question: What are your top research practice and policy priorities for advancing equitable healthcare for people with disabilities?

Across all those groups and all the areas, the number one priority was consistent documentation of patients' disability status, both in the EHR and in national surveys. Then, finally, as mentioned, I lead what is called the Disability Equity Collaborative. As part of this collaborative, we have a learning collaborative of 50-plus health systems who meet every other week to talk about what they are working on and how they can advance equitable healthcare in their organization. I can assure you that all 50 of those organizations are actively working on some level on how to better document patients' disability status. Unfortunately, not a lot of them have figured it out. We are all working on this together. We did interviews with them to dive into understanding why this is so challenging. Part of what they have identified as challenging is the lack of policy and standards over what questions should be asked, what data elements should be in the EHR.

Because we don't have those standard standardizations, there is not a standard EHR build. Many organizations are developing their own builds and that is taking a lot of time and effort for them to figure this out. Again, as part of that Disability Equity Collaborative, we have a workgroup on documenting disability status. Epic is actively involved, working with us We have about 30-plus members. We are working together to identify what standards should be in electronic health records. What data elements, but also identifying how the EHR can be maximized to provide equitable healthcare.

Next slide. Getting into the nitty gritty **[inaudible] [00:30:50]** questions. We could spend days talking about disability questions, but we are going to limit our discussion to these seven questions. These seven questions are a combination of the ACS, or the census question, and then the Washington Group question. The Washington Group is an international group of people who put together disability questions. These are the seven categories. I won't necessarily go through all the different categories of disabilities, but again, we did research on these questions asking patients, providers, and other stakeholders to identify what the best questions are that we should be asking. We started with a blank slate and we landed with these seven questions.

One of the comments in the chat, also recognize that disability does change over time, and so these questions are not a one-and-done deal. They need to be asked repeatedly and followed up, because again, disabilities can change over time.

Next slide. Thinking towards the future, we see there are a few elements that we would like to put out there in future rounds to be considered. One is a learning disability question, a question about mental health disability, and then a question about autism and social disability. You see under learning and mental health, we do have some recommendations about what those questions could be. I think we are, as a field, still

figuring out what the best question is for autism and social disabilities. Also, there is active discussion about healthcare accommodations. We are talking about accommodations that are provided in the healthcare setting that help individuals with disabilities participate in their care. I also want to throw out caregivers. Healthcare organizations are actually legally mandated to also provide accommodations to caregivers. For example, parents who have disabilities. We need to also be able to track the caregiver's disability as well. Next slide. I will turn it over to Silvia.

Silvia Yee

Thank you, Megan. I was just going to this slide. There are a few things we recognize about disability questions, and that there is no perfect question. We know that disability is a socially constructed concept. We have finally come to a place where many healthcare entities collect race, ethnicity, and sexual orientation and gender identity questions and information in the healthcare context. We do so not because these personal characteristics are necessarily and inherently influential on health. We do so because these characteristics interact with the healthcare environment in multiple ways. We can identify those ways with data.

Disability can be seen as more complicated because the factor of disability usually does have a direct connection to health, but there is also an interaction with the environment. In this case, the physical, social, cultural environment in which healthcare takes place. That has never been captured well and cannot be captured without demographic data on functional limitations. This is what we mean by disability as a socially constructed concept. We know that not everyone with an impairment will identify as having a disability. For example, many older persons who have a newly acquired disability or functional limitation don't necessarily think of themselves as a person with a disability, which is also why the questions that we have recommended are written the way they are. We acknowledge that language changes over time and is affected by cultural understanding and translation. Despite these challenges, people with disabilities, the disability community, needs to have this information collected and cannot be asked to wait any longer.

Next slide, please. To go through some of the reasons for the urgency, one of the number one reasons is what we have gone through in the last two years and continue to go through now with COVID-19 and the public health emergency. The lack of disability information negatively impacted access to personal protective equipment, vaccination prioritization, critical support persons, and the ability to recover health. Disability is not a diagnosis and a diagnosis is not a disability. It is important to have detailed, accurate clinical information, as our co-chair Arien has said. However, that clinical information still does not capture all aspects of functional limitations and needs.

I will give one example that I went through a lot in 2020. My organization worked and received many complaints from individuals with disabilities who typically work with support persons and who need support persons, potentially for communication needs and for assistance with activities of daily living. As the pandemic swept across the nation, most hospitals imposed visitation limits and would not allow anyone to have a visitor with them. There was, however, no understanding that a support person is not a visitor and there was no understanding that Civil Rights laws continue to apply even during a pandemic.

Not having this information, you would have individuals with intellectual and developmental disabilities who would have to go to the hospital, whether for COVID or another reason, and a family member could not go with them. An essential support person could not be with them, which then meant their condition, their

health overall would deteriorate greatly. We heard of an individual with developmental disabilities who could not keep their mask on. Their family member, who would typically be there with them and would be able to help them do that in a hospital environment, was not allowed and that person actually did die because they could not keep their respiratory mask in place.

This is not something you would necessarily know from a diagnosis, the need for a support person or that assistance is needed. The same thing is true for something like the sequential and crisis standards of care which were applied. That exacerbated the whole situation because individuals with disabilities who are in hospitals, if their condition deteriorated sufficiently, they could, in a surge situation, be denied COVID treatment and denied respiratory treatment. Anything that would lead someone to have their health deteriorate, even someone with a vision disability, because the sequential organ failure, the SOFA scores, relied on things like being able to respond to someone's eye movements, a patient's eye movements could be tracked or their ability to respond to questions. All of that is affected by functional limitations and the functional limitations are not in the electronic health record.

The provider applying and finding out the SOFA score, determining the SOFA score, could not know that there were disabilities that affected that score. These are things we heard about, that we were phoned about, that we heard directly from people with disabilities about. Another reason is that a lack of disability demographic identification means less funding, less understanding, less inclusion, and greater stereotypes. It was very hard in California to get the state to understand the risk that home and community-based users in the community were under because support persons were coming to their homes to assist with tasks where social distancing is impossible. We even challenged without demographic information the assumption that poor health outcomes are inevitably linked to the fact of a disability and the belief that there is no such thing as a disability-related health or healthcare disparity.

Arien Malec
I wanted to insert a time check. This has been fantastic. If you want to do maybe a quick cleanup and we then can move to the next panel.

Silvia Yee
I will. I would like to move to the next slide. I think you can go through this slide and certainly see the reasons why we feel the inclusion of disability information is so vital right now. We wanted to go on to our recommended action steps. After all of this information that we provided you, the very first action step is we think it is very, very important to include disability as these disability elements. It is important to include the Washington Group and the ACS disability questions in electronic health records as a demographic factor.

Second, we highly recommend that a patient reported data collection approach is used. Third, we recognize that this is a first step. Future efforts can and should focus on accommodations but we won't get there without this first step. Many people in the disability community, many advocates, have waited a very long time for a first step to be taken. Fourth, we support the use of disability data to improve clinical care and address healthcare inequities that have been so hard for us as advocates to establish. Thank you.

Arien Malec
Thank you so much. As I think everybody can appreciate, truly an amazing presentation and a presentation from the ground, improving the lives of all of us in the course of our history. We are going to go on to Matt

Elrod, who is going to talk to us about the informatics view of capturing functional disability and cognitive status. Matt, quickly, over to you.

Presentation (00:42:26)

Matt Elrod

Thank you very much. Next slide, please. I am Matt Elrod. I am a physical therapist. I practice part time. My full-time job is as a clinical informaticist with MaxMD, where I try to help share information among clinicians and various users. Next slide. I have three objectives today. What I would like to do is introduce everyone to something called the International Classification of Functioning, Disability and Health, the ICF. I would also like to talk about recommending alignment between the ICF and draft USCDI V3. And then finally, talk about recommendations or similar approaches between these various data classes and what has been used in social determinants of health.

Next slide. The ICF is a classification system that has brought to us by the World Health Organization. We know them well for the ICD codes, specifically ICD-10, that is used now. They also have other classification codes looking at healthcare interventions. Today, I am going to focus on the classifications of functioning, disability, and health.

Next slide, please. To start off, let me tell you a little bit from a clinical perspective. Again, I am a physical therapist. I view the world through mobility, how people move around and interact in their environment. If we take an example of the ICF, or if we look at the ICF, it is used to help describe people at all ages and all levels of ability, and even to help identify if they have any disabilities. What I want to do is tell you a story about Joe. Joe is a patient. We will say he is an individual that has shoulder problems. These shoulder problems are preventing him from gardening, something that he enjoys. Joe is here in the middle. There he is out walking with his dog. He has no problems whatsoever with mobility. He can walk on level surfaces. As a therapist, I need to be able to document that. I can document that through clinical tests. I can talk about the problems that he has, these impairments of pain and mobility in his shoulders. I can talk about limitations of lifting his arms up, and I can talk about these restrictions he has in performing his habits or hobbies of gardening.

Let us use the common use case that people talk about, COVID. Joe gets COVID. Now he is admitted to a hospital. Now, we can use these same constructs, these same ways of describing his movement or his impairments. Now he has impairments of a respiratory system and he has impairments of generating muscle functions and endurance. He also has limitations of decreased mobility and his inability to walk short distances. Joe has a long road ahead.

Next slide, please. All those words I just used to help describe Joe came from a construct of the International Classification of Functioning, Disability and Health. This is a general slide that has shown a lot of times to talk about how there are these interdependencies between someone's health conditions or disease, their body's functions and structures, activities and participation, and environmental factors. That is something I heard you talk about at the beginning of the call, about accommodations for things as well as personal factors, things that can't be changed. The things in red are very clear constructs that the ICF helps to cover.

Next slide, please. Here, we see in this slide is showing some of the secret sauce, if you will, of ICF. How do you look at ICF or how does ICF help you understand, in angling terms, in other words what someone can do, but then also describe disability, or things someone has problems with doing? The ICF is built to do that.

Next slide, please. How is ICF built to do that? ICF has these components, as I have said before, the body functions, structures, activities, limitations, and environmental factors. It has a hierarchical structure. This hierarchical structure has chapters, numerous chapters, in each one of the components that you see listed over to the left. What you will notice is you can then have various levels of more discrete information. It can be moved down and down to where you have more specifics about how someone is moving around, or interacting, or functioning in their environment.

Next slide, please. Let us go back to Joe for a minute. To start off, on the left side of the screen, you can see when Joe was just having an issue with his shoulder problems, that he had no issues or disabilities related to his mental functions or mobility. There were no problems there. We could talk about things about his health status and how he is functioning. But as Joe now has COVID, let us get into more discrete information about how we could share specifics about his mobility.

Next slide, please. If we start looking at this hierarchical model of ICF, and we talk about mobility, as you go down and look at the chapters, these are just a representation of some of the chapters that are in ICF, you can talk about mobility. You can talk about walking and moving. You can be more specific in talking about just walking. Then, you can talk about how he is able to walk short distances. Now, the key thing to remember here is it is not dependent on any specific standardized test and measure. I heard earlier that there is no perfect question. I would agree with that. There has so many instruments out there that are used in the physical therapy domain that there is not a perfect question that addresses everyone from either end of these spectrums and across all ages. However, the ICF gives you a construct about how to share like concepts.

Next slide, please. This gets us into talking about how we could look at this ICF framework and understand how it relates to draft USCDI. Again, as I mentioned, the ICF framework is operationally defined; it is something that has been out there for a number of years. It is used in clinical rehab communities and it is very common verbiage used by physical therapists, occupational therapists, speech-language pathologists. We use that in our education. The terms are patient centric, so when you use these words or are talking about how someone is interacting in an environment, you have the ability to use words that are meaningful for a patient, or their caregivers, or loved ones. We also know that there are payers and clinical communities that use standardized instruments out there. I listed a couple of them that may be well known. All of their questions can be mapped back to ICF terms and domains in this framework. Again, it supports both functioning and disability.

Next slide, please.   With that, I want you to take away from this that, if we can use a construct, and we start looking at functioning, so if you roll up that mental status and the functional status and we start using an ICF construct, we have the ability similarly to what was done in the Social Determinants of Health, about how you can have this hierarchical structure to help share meaningful information regardless of where someone is in the continuum of care. Again, this is just a visualization of appreciating that structure of body or functioning. You are looking at body functions and you can have mental functions and you can even

break that down further. The same is true as I demonstrated earlier with mobility, again, the ability to break that down further.

Finally, our last slide. As we look at representing these functional things, you can do something that has very similar to what was done with Social Determinants of Health. In Social Determinants of Health, the concept of representing that, it occurs in many data classes within USCDI as problems, as assessment and treatments, and as goals. Similarly, when you look at functioning and you talk about that, again, whether it is an enablement model of explaining where someone is or a disability model about what problems they have, you can use in the data classes things like providing structured or unstructured information about how someone is functioning. That is key. It is key that it is not just a single standardized question.

Again, these standardized questions out there can be represented in LOINC or other ways you can roll that up or identify specific ICF codes and share that information to more clearly and succinctly explain how someone is moving around in their environment.   You also can use these problems. You can identify these impairments, these limitations, or restrictions on how someone is, again, functioning or what their disabilities are in their community. Assessment is a word that gets very confused very easily. When I use the term assessment, I think about it as what goes on in between my ears. What is the clinical problem solving that I am doing to document what the problem is and now what my treatment plan is?

Assessment. That word gets used a lot. Sometimes people use it to talk about the instruments that are used. However, again, I am clearly trying to say this assessment of what is going on and being able to represent those things, we can use ICF terminologies to help us move forward in that world. Finally, as we are talking about goals, about the patient's desired outcomes, you can use these functioning terms about, "I would like to be able to walk on unlevel surfaces without having any problems." Again, these are ways that we can communicate very clearly and across multiple domains how the activities that I do as a physical therapist can help support a patient. When I communicate to a physician provider, or other healthcare providers, I can use this common language and this common structured information to help share those important pieces of information.

Arien Malec
Matt, sorry for the interruption. Would you mind going to the recommendations slide? We have one more panel to accommodate as well as **[inaudible - crosstalk] [00:54:07]** –

[Crosstalk]

Matt Elrod
The recommendations slide was already included.

Arien Malec
Cool.

Matt Elrod
If I went through that a little too fast, that was back a couple of slides. If you want to take a look at that again, quickly. It is a pretty clear recommendation of adopt the ICF.

Arien Malec
Adopt ICF. Okay.

Matt Elrod
You got it. Then, look at those others.

Arien Malec
Awesome. Thank you so much. Apologies for the time limitations. This is a complicated topic that we are trying to do in 10-minute increments. We can go on to the next panel discussion. Thank you for that. I feel like Holly and Terry are rock stars and need no introduction but I will suffice to say that both of them have been tirelessly working to improve interoperability in the domain of longitudinal care planning, geriatric care planning, long-term post-acute care planning. The list goes on. They have been at work to make sure that we have the interoperability needed so our healthcare system works as a system longitudinally in addition to its current functioning as encounter-based workflows. With no more fanfare, I will turn it over to Holly and Terry.

Presentation (00:55:43)

Terry O'Malley
Great. Arien, thank you very much, and thank you to the panel for inviting us today. Thanks to the other speakers. It was informative and very thought provoking. We are going to keep things a little more directed at reshuffling the chairs in the USCDI. We are going to touch on these four topics. Dr. Miller and I will tag team on the presentation. She is going to do the color commentary and I will do the play by play. We are just going to propose that we retain health concerns as a separate data class, rename health status as health status/assessments, and provide a definition for health status/assessments, and then recommend some other standardized assessments that would be useful. All of these fit within the construct that Matt just presented.

Next slide, please. Okay. This is pretty easy. We are thinking that health concerns represent to me at least, a different concept than either a problem or a health status, because a health concern is not objective in the sense that a problem or a status is or are. Then, health concerns also require further action before it is defined enough to become either a health status or a problem. That action is usually an assessment, not in the way that Matt used the term assessment, but assessment is a standardized process for evaluating the significance and extent and characterization of the concern. In a sense, again, it is different than a health status and probably most importantly, from my perspective, is that health concern is the mechanism by which the individual and/or their caregiver provides input into the care plan. It helps prioritize items to be addressed. There is no other place in USCDI that this input comes in.

I am a retired geriatrician. In clinical care, health status plays a different role than the health concern. Thinking that moving concerns under health status confuses different concepts and downplays the importance of health concerns as the individuals' means of directing care. That is our pitch there. Holly, do you have any additional thoughts on that? We can move to the next slide.

Holly Miller

Thank you so much, Terry. I echo Terry's comments about wonderful presentations and thank you for inviting us. I think that the other thing with health concerns is it really indicates further workup is required. You are not at a problem, you are not at a health status, but there is a concern that requires more looking into. Go ahead, Terry.

Terry O'Malley

Okay. Next slide, please. All right. This one is pretty straightforward too, proposing that we rename health status to health status and assessments. The reason for this is that, again, health status is a condition or a state of being. You are pregnant or not pregnant. You are at high risk or low risk for falls. Standardized assessments are the process by which health status is established and there is no designated bucket, if you will, within USCDI where you can put the results of standardized assessments. I don't think of those results as a test result. They are different. It is much more of a process, I think.

Some of the confusion, and Matt touched on this, arises because assessment in the currently existing data class assessment and plan of treatment, is a different assessment. It is really the clinician's conclusions based on your available data. It is not in itself a process. Assessment in a renamed health status/assessments data class would combine the process of establishing health status with the health status itself and provide a place for assessments within USCDI. Again, on to the next slide. Holly, please add?

Holly Miller

I think, in our discussions with AI around this and what Terry just mentioned, we are thinking of standardized SOAP notes, subjective, objective, assessment, and plan where the assessment is generally a diagnosis. Therefore, we really wanted this in a separate location with health status so it became very clear that these were like standardized assessments that had been given for the patient that had a result or a value.

Terry O'Malley

Okay. We propose a new definition for the health status/assessments data class. This is where you put a state or condition indicated by the results of a standardized assessment and compare it with problems and with health concerns with the current definitions associated with them. The relationship of these three data classes, if you will, is interesting because it is a very fluid, dynamic connection. The connection between the health status and the health concern is an assessment, an act in progress. The result of an assessment, often the result of a health concern, is a health status, which is a state of being, such as pregnant or not pregnant. The state can be different from the original health concern.

In this case, it might have been. "Am I pregnant," as the health concern, and the health status is now either pregnant or not pregnant. This new health status may in turn create a new health concern or problem. The concern can be either, "Am I pregnant when I did not want to be," or, "Am I not pregnant when I wanted to be?" The resulting problems can either be pregnancy or failure to conceive. Also, it might not be a problem at all. "I am pregnant and I want to be," or, "I am not pregnant and I don't want to be." This is a fluid relationship among these three data classes. I think of clinical care in this way. These are always in a fluid relationship.

This leads to the final slide. Go to the next slide, please. That is the data class itself. On the left is what is proposed and on the right we have some additional recommendations. The following three or four slides

go into much more detail on the recommendations. They are not something we have to go into in any detail today. We will stop at this slide. We will just say we are taking up health concerns, and the subclasses listed on the left are all important and they are excellent choices, those initial set. We recognize this is a start. This is not the end of the long trail, but it is a great start. These are all important.

Functional status will need to include a bunch of other elements such as mobility, incontinence, and ADLs, and IADLs, and emphasize abilities. There is an extensive list of commonly used functional assessments and they are going to have to have a home somewhere within USCDI. The functional status bucket will need to be large enough to provide a place for them. Disability status I think is important, not so much for the reasons that have been previously given, although those are all important, but just that there are major sources of funding and payment within the U.S. healthcare system that rest on disability. Social Security, workers' compensation, VA benefits are all disability statuses and there needs to be a very clean place where these constructs can exist within USCDI. As a geriatrician, life is about function and mental status, function and cognition. Mental status is going to need to be blown up as well to include cognition and mood and behavior. Let us just stop there. And just –

Holly Miller
Terry, if you could go to the next slide. I think there were certain things we felt were critical. In transitions of care, there really were certain elements we thought were critical in caring for the patient. I think the list in the previous slide captures that and this is just a little bit more detail on what we thought was absolutely critical for transitions of care to be able to adequately care for a patient, particularly in the LT path world.

Arien Malec
All right. I apologize. This is the classic thing of short-shrifting panels two and three because there was so much really amazing content in panel one, but I think in the totality, we have covered an amazing amount of ground. We are going to go to organized Q&A. As a reminder, we have, I think, about 15 minutes for overall Q&A before we go to public comment. Depending how much public comment we receive, we may be able to go back to Q&A. Steven has been tracking some of the comments in chat and we have a couple of folks who have raised their hand. Maybe I will go back and forth between hand raising and bringing forward some of the comments in the chat. Hans, let us start with you.

Hans Buitendijk
Sure. Two questions to two different panelists. First to Terry. Welcome, Terry. Good to see you again, and Holly. You are introducing combining assessments with health status. There is currently an assessment and plan of treatment to class as well. What are your thoughts on splitting that one up and moving the assessments together and have them all in one place in light of the arguments that you made? That is one question. The second question I had, if we have time, we can do later as well.

Terry O'Malley
Sure. Thanks, Hans. Obviously, we think it makes a lot of sense to move assessments, again, with the definition that they are a standardized process of evaluating a particular concern or status rather than, as I think someone mentioned in the chat, a state of art. The assessment in the assessment and plan of treatment group comes from the old SOAP note and how clinicians work. They are two different concepts. Yes, I think we ought to move the assessments over. I think, however, that would leave us with a nice

bucket of plans. When we get to the point of thinking about plans of care and treatment plans, we are probably going to want a place to put those as well somewhere in USCDI. Repurpose that data class.

Arien Malec

Steven, before I go on to Raj, are there any folks who have not already raised their hand with an important comment that we want to bring forward?

Steven Lane

Absolutely. Yeah. There has been a rich discussion in the chat. I think most people have figured out that they want to send their chat comments to everyone. All those chat comments sent to everyone are captured as part of the public record and are going to be made available as part of the minutes of the meeting. Thank you for that contribution. There was a specific recommendation early on in the first presentation about whether or not disability status or functional limitations belonged in this new health status data class or whether they perhaps would better be suited to demographics.

That is largely an academic question because, as has also been discussed in the chat, it does not really matter where a data element sits in the hierarchy. It is still in the USCDI. While I think there may be some reasons why we want to move things around, as Terry and Holly in particular have recommended and as we will consider as a workgroup, the key is that we get things in the door. I will also observe there have been a number of comments about the potential risks related to adding some of these data elements, that perhaps by measuring or sharing this data, this could indeed worsen inequities or disparities for certain patients. I think that that has always a risk. These are data that are already being collected by some providers.

My personal feeling is having them standardized and having a way to incorporate them into standardized exchange will net improved care, but we certainly do need to keep in mind that there are always unintended consequences that we should be watchful for. I think David has had a lot of comments back and forth about the concerns that adding such things requires their measurement, which could then impact clinical workflows. To be clear, just because something is in USCDI, does not mean it must be collected at any given clinical encounter. However, if it is collected, it provides a way to standardize that data and its subsequent sharing.

Arien Malec

I wonder, Steven, just on the topic of introducing the opportunity for discrimination if we might go to panel one and get a very brief response? Silvia, Bonnie, Megan, whichever of the three of you wants to answer. Maybe Silvia, with your Disability Rights hat on, I wonder if you could very briefly touch on the subject of balancing collecting data to improve care in health and for advocacy versus the risk of future discrimination. I know that has a complicated topic in go over in a one-sentence answer, but I wonder if you could briefly comment.

Silvia Yee

If I were forced to one sentence, I would say that we do have protections we can put in place. Protections are very important, particularly in the age of artificial intelligence and algorithm use, et cetera. Without this data, we cannot even track existing discrimination. We are not in an ideal status quo right now so as to not

disturb anything and not introduce more discrimination. We are in a place where there is discrimination and we need to capture it.

Arien Malec
Thank you very much. That is super useful. Thank you.

Steven Lane
Go to hands.

Q & A on Presentations (01:12:20)

Arien Malec
Bonnie also comments that we do more harm by not collecting this data and she approaches this from the perspective of epidemiology particular to discrimination. We are going to go to Clem. Clem, you're still muted.

Clem McDonald
I am sorry. I fully support Terry's idea about how the assessment and plan and assessment is quite different from an assessment where an assessment is actually a survey instrument or collection of stuff that has been verified and validated that you can see a scale on it. I am for that. However, I don't agree with emphasizing making a separate creature called the concerns over problem, because I think the original definition included anything anybody was worried about, provider or patient, would be a problem. I think it is going to be hard to manage both lists and to know when is which, which is a what. A patient has a heart attack, that might be a concern, but it is also a problem. I think it can be hard to sort that out. We are not maintaining problem lists perfectly yet anyway. If we add another list, I don't know how it is going to work out. Just a thought.

Arien Malec
Clem, I will remind everybody that health concern is actually not part of our remit because it is already part of USCDI.

Clem McDonald
Okay.

Arien Malec
It is preexisting. David, over to you.

David McCallie
Thanks, Arien. My question is maybe to any of the panelists who would like to respond. It is about the adequacy of a simple structured assessment as a starting point for capturing some of this information. We have had debates in our panel in the past about the relative merits of capturing free text, full complete sentences, describing a situation versus capturing some kind of a structured assessment. I was impressed with some of the example assessments that you showed, that they were simple enough to be not overwhelming. However, I wonder are they adequate for capturing the information that you are recommending we should be capturing. Just a broad thought about the current state of assessments. Are

structured assessments a good starting point or should we stick with text for the time being and then structure it later?

Terry O'Malley
This is Terry. Short answer, yes, they are adequate. Unfortunately, there are thousands of them, all validated and standardized.

Steven Lane
As I noted in the chat, we have the opportunity, and ONC has done this already within this data class, to identify, for example, that this sort of an instrument or this particular instrument would go into this new data class. I think there is value in that, as outlined in Terry's and Holly's slides. We did some of that work last year with SDOH assessments, identifying specific LOINC instruments that could be used. I think if we do that, ONC has the option of including that level of specificity in the V3 specification.

Holly Miller
I completely agree. I am sorry, to Arien's point, that makes them codifiable and interoperable and that is what we are shooting for as patients' transition, for that information to go with the patient.

Steven Lane
We have three minutes to public comment and I want to get some of these hands down. Alexis?

Alexis Snyder
Yes, hi. I have a concern over including assessments into the health status. Not all assessments, whether we are talking about standardized assessments or even just a provider's assessment of the situation without using a standardized test, will classify a diagnosis or a health status for somebody. Those are still true problems for a patient, or even a concern brought up by a caregiver. I am not sure that lumping together your health status based on an assessment, again, either standardized or just an assessment as an observed provider, really makes sense because that is going to disqualify a whole bunch of people who have real problems, legitimate concerns, and diagnoses that are not diagnosed yet, and particularly those with rare disease and other things that have not been diagnosed. I think putting it into status does not make sense because your health status could still be very different from what is shown up by an assessment and especially a standardized assessment.

My other piece, I would just say, is to the problems versus concerns. I would be very opposed to the idea of saying that a patient concern is not necessarily an actual problem. I think when we talk about discrimination and patient voice and not taking into account what is happening with the patient at the moment, considering something a concern and that it is not necessarily a problem is very subjective to the person who is evaluating that. I really think we walk a slippery slope by saying a concern isn't necessarily a problem.

Arien Malec
Thank you. Grace?

Grace Cordovano

There is a lot of work done with Social Security disability benefits. Is there any way that could be added to the work that is being proposed for inclusion in draft V3 to help enhance these conversations about health status, for example, disability status, functional status? Would capturing and linking that information here be helpful?

Arien Malec
Grace, I had exactly the same thought because I have been through the pain of trying to justify or document disability status with Social Security. I believe the way this is going to happen is that work will go through USCDI+. I would be hopeful that the work we are doing here advances the cause. I think we know right now it consolidates CDA out of the box. It does not fully address all of Social Security's concerns. They published an implementation guide for CDA-based data collection that does get the full documentation required for disability determination.

Steven Lane
Okay. Let us hold the remaining questions and go to public comment. I know a number of folks from the public are looking forward to sharing some ideas with us. Then, we will come back to the raised hands.

Public Comment (01:19:34)

Mike Berry
All right. Thank you, Steven. We are going to pause now and open up our call for public comments. 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 happen to be on the phone only, press *9 to raise your hand, and once called upon press *6 to mute or unmute your line. Let us pause here to see if we have any raised hands. Forgive me if I pronounce your name incorrectly. I see Michelle Dougherty.

Michelle Dougherty
Dougherty. Thank you.

Mike Berry
Thank you. Go ahead.

Michelle Dougherty
Thank you. My name is Michelle Dougherty. I am a senior health informaticist with RTI International. My background includes 15 years of experiencing advancing interoperability to support aging and disabled populations to identify gaps in the interoperable data classes and proposed data classes to address the important healthcare needs of this population. Related to the focus of today's workgroup meeting, I have submitted comments on the gaps around function, mental status, disability status, and early iterations of the common core data for interoperability. I've also proposed data and standards that are included in the interoperability standards advisory and proposed the functioning data class that is currently referenced in the V3 for mental status and aligns with the functional status proposal that is currently in V3 that Dr. Miller submitted.

With that background and context, I would like to relay the following comments around the presentations today. First, appreciation for the expertise and recommendations of all the presenters that are informing this important work for consideration by the workgroup and their recommendations. Second, just to support

Dr. O'Malley's and Dr. Miller's presentation and proposal for the data class to be renamed to focus on health status and assessments. In work that I've done around the functional and mental status area in trying to differentiate between observation versus problems, I just wanted to note that I felt agreement with their recommendation that health status is more aligned with problem and therefore perhaps is not part of this heading. I understand the limitations as well.

Then, also agreement with SDOH items which are often based on screens and status information and potentially there is some better alignment in the health status assessment class that is being discussed today. Also, to address a comment that came in today around the current assessment and plan of treatment, I would like to express my support for updating that naming to something that was brought out here today as plans and treatments. For example, that could address care plans. It could address treatment plans and orders, areas that are gaps that we have identified in our analysis of USCDI and the current classes that have been submitted.

I have just two final comments. One is to endorse Matt Elrod's presentation on the use of ICF as an organizing framework in the functioning space. We work together on the PACIO project. It is a firework FHIR workgroup and as well I work on the CMS data library health IT workgroup. As part of the team that is supporting the development and evolution of the functional and mental status, FHIR implementation guides, we have worked with the FHIR workgroup, the community meeting, and we hit challenges that were really significant in the difference of opinion based on clinical expertise when discussing functioning and how it should be organized and how it could be expanded over time. When the framework of ICF was brought into the discussion, it provided a credible, well-researched organizing structure for the IG as well as future expansions. I wanted to share that experience and how it helped bring consensus to the workgroup and a path for future.

Arien Malec
Thank you.

Michelle Dougherty
I also wanted to note that **[inaudible - crosstalk] [01:23:53]** –

[Crosstalk]

Arien Malec
I think we are at time right now for the three-minute public comment. Thank you so much. Who is next up?

Steven Lane
I don't see any other hands raised for public comment at this time. I will turn it back to our co-chairs.

Arien Malec
Okey doke. Why don't we go to Ike?

Steven (Ike) Eichner
Thank you so much. Listening to today's conversation makes me think we need both some structured and unstructured data elements. We are looking at an unstructured data element to account for assessments

that are being undertaken right now, looking at individuals with rare conditions among others because it is going to be a very long time before we can get every assessment across every condition codified with standard results. The ability to share that specific assessment information across the care team for those individuals becomes important as we are looking at shifting information between physicians, and social workers, and physical therapists, and the like. I think having that flexibility would be really, really important. Having some structured data elements to at least communicate high-level needs as a starting place would also, I think, be helpful and be able to help us sort information or categorize information at a broader level. I think we need to look at this as an evolution. We are going to eat this elephant one bite at a time and not in one big mouthful.

Arien Malec

Thank you for that. I just want to remind everybody because there has been a bunch of discussion on this, in many ways what we are talking about is pairing a LOINC code with a slot, with no USCDI determination of what is in that slot. That overall construct can serve both structured assessments and questionnaires as well as unstructured observations, or patient observations, or self-assessments. That has the place that we are at is. Hey, let us just have a pairing of a LOINC code and a slot as opposed to the ability to capture all the detailed information that comes out of an assessment. I am going to turn it over to Mark S. for a question.

Mark Savage

Thank you. First, so grateful to the three presentations and the presenters. Just amazing. Second, I am glad that the workgroup and ONC staff will be curating the chat because there is some important comments in there to be folded in. Lastly, to my clarifying question, the first presentation emphasized the importance of self-reporting on disability status. I did not discern from the ICF alignment that that was a self-reporting. It seemed more like an observation. I just wanted to confirm because self-reporting is critical here.

Matt Elrod

This is Matt Elrod. I will address that. ICF is absolutely used for self-reporting as well as for clinical observation. It can be used in multiple constructs of a patient reported outcome instrument and it can be used to represent those identified problems from the clinicians.

Arien Malec

Thank you. Clem, you have two minutes, and then we have to wrap up because we are at time. Go ahead, Clem.

Clem McDonald

Thank you. I would like to follow up on Terry's comment that there are thousands of these surveys. they are quantitative. I think the issue is we should be doing questionnaires and survey instruments that are validated because they provide a quantitative thing, especially if they are not monstrously long. However, we ought to pick them because the thousands of them really inhibits the use of them and makes it a problem for comparing. There should be some effort to say for this purpose this one or these two are really good. I don't know how we can get to that because it has been a problem for a long time and it is very competitive and sometimes we are charged for it. Having a standardized instrument where you get a quantity is way better than an assertion of something or other.

Arien Malec

Yeah. I think we heard from the first panel that if we do nothing else, the ACS Washington assessment is the one to use. I would also comment that in USCDI land we are blissfully unconcerned with the actual assessment because we get to parameterize that to a LOINC code.

Steven Lane
We are at time, Arien.

Arien Malec
We are at time. Exactly. It has been fantastic.

Steven Lane
We want to thank everyone for your presentations, for your comments, for your discussion. We will assure the workgroup that we will come back together next week and dig down into the specific recommendations that have come out of these presentations. We continue to invite all of you to capture your comments in the spreadsheet and we will return there. I also want to make a comment that Hans has done tremendous work fleshing out our spreadsheet regarding mapping to the various standards, including FHIR, and we will go through that next week as well.

Arien Malec
I just want to thank the panels. Truly an amazing day. Hopefully everybody has learned a ton, as much as I have. As Steven says, we will take the output of this and turn it into work and recommendations via our usual mechanisms. Thank you so much.

Steven Lane
Have a great day.

Adjourn (01:30:06)