



# Health Information Technology Advisory Committee Interoperability Standards Workgroup Virtual Meeting

## Meeting Notes | March 1, 2022, 10:30 a.m. – 12:00 p.m. ET

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### Executive Summary

The focus of the Interoperability Standards Workgroup (IS WG) meeting was to continue to work on Charge 1, which included reviewing the new data classes and elements from draft Version 3 of the United States Core Data for Interoperability (draft USCDI v3) and considering data classes and elements in Level 2 that might be appropriate to add to USCDI v3. TF members heard three presentations regarding the Health Status data class followed by Q&A.

There was one public comment submitted verbally, but a robust discussion was held via the chat feature in Zoom Webinar.

### Agenda

10:30 a.m.	Call to Order/Roll Call
10:35 a.m.	Workgroup Work Plan
10:40 a.m.	Introduction to Health Status Data Class (Draft USCDI v3)
10:45 a.m.	Presentation: Closing Disability Disparities: EHR Data as the First Step
11:00 a.m.	Presentation: Capturing Functional Disability and Cognitive Status using ICF
11:15 a.m.	Presentation: Proposals: Health Concerns and Health Status Assessments Data Classes
11:30 a.m.	Q & A on Presentations
11:50 a.m.	Public Comment
12:00 p.m.	Adjourn

### Call to Order

Mike Berry, Designated Federal Officer, Office of the National Coordinator for Health IT (ONC), called the meeting to order at 10:31 a.m. and welcomed members to the meeting of the IS WG.

### Roll Call

#### MEMBERS IN ATTENDANCE

**Steven Lane, Sutter Health, Co-Chair**

**Arien Malec, Change Healthcare, Co-Chair**

Kelly Aldrich, Vanderbilt University School of Nursing

Hans Buitendijk, Cerner

Christina Caraballo, HIMSS

Grace Cordovano, Enlightening Results

Steven (Ike) Eichner, Texas Department of State Health Services

Sanjeev Tandon, Centers of Disease Control and Prevention (*Attending on behalf of Adi Gundlapalli*)

Rajesh Godavarthi, MCG Health, part of the Hearst Health network

Jim Jirjis, HCA Healthcare



Kensaku (Ken) Kawamoto, University of Utah Health  
Hung S. Luu, Children's Health  
David McCallie, Individual  
Clem McDonald, National Library of Medicine  
Mark Savage, Savage & Savage LLC  
Michelle Schreiber, Centers for Medicare & Medicaid Services (CMS)  
Abby Sears, OCHIN  
Ram Sriram, National Institute of Standards and Technology

## **MEMBERS NOT IN ATTENDANCE**

Thomas Cantilina, Department of Defense  
Leslie (Les) Lenert, Medical University of South Carolina  
Aaron Miri, Baptist Health

## **ONC STAFF**

Mike Berry, Designated Federal Officer  
Al Taylor, Medical Informatics Officer

## **Key Specific Points of Discussion**

### **TOPIC: OPENING REMARKS**

Steven Lane and Arien Malec, IS WG co-chairs, welcomed everyone. Steven reviewed the agenda for the meeting and invited all attendees to share comments, questions, and feedback in the public chat in Zoom and reminded members of the public that they were welcome to share verbally at 11:50 a.m. during the public comment period.

### **TOPIC: WORKGROUP WORK PLAN**

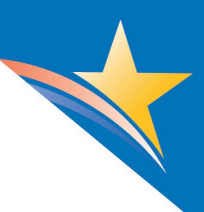
Steven highlighted areas of focus, which were detailed in the [IS WG presentation slides](#), and reviewed the charges of the IS WG, which included:

- Overarching charge: Review and provide recommendations on the Draft United States Core Data for Interoperability Version 3 (USCDI v3) and other interoperability standards
- Specific charges:
  - Due by April 13, 2022:
    1. Evaluate draft Version 3 of the USCDI and provide HITAC with recommendations for:
      - 1a - New data classes and elements from Draft USCDI v3
      - 1b - Level 2 data classes and elements not included in Draft USCDI v3
  - Due June 16, 2022:
    1. Identify opportunities to update the ONC Interoperability Standards Advisory (ISA) to address the HITAC priority uses of health IT, including related standards and implementation specifications.

Steven explained the focus of the meeting was on the Health Status data class, which is a new data class that has been proposed for inclusion in the draft USCDI v3. He explained that some of the data elements have already been present in prior versions of USCDI, and ONC received feedback that these could be moved into this new data class while other data elements are brand new. Steven emphasized the opportunity to advance the interoperability of data related to health status, disability status, functional status, etc. He described his own experiences related to his role as a practicing primary care physician and, recently, as a patient. Steven stated that this kind of discrete data is often lacking and urged the WG to support moving these items forward with appropriate specifications.

### **TOPIC: INTRODUCTION TO HEALTH STATUS DATA CLASS (DRAFT USCDI V3)**

Al Taylor presented an introduction to the Health Status data class that was included in draft USCDI v3 to



address the following health-related matter of interest, importance, or worry (to a patient/patient's family/patient's healthcare provider) elements, which included: Health Concern, Disability Status, Mental Function, Functional Status, Pregnancy Status, and Smoking Status. This data class was detailed in the [IS WG presentation slide deck](#), and AI described the data elements, background information, and applicable vocabulary standards and value sets. He stated that the focus of the current meeting would be Disability Status and Functional Status, which are related and are typically structured assessments. He discussed feedback ONC received on this data element. He shared information on Disability Accommodations, a data element submitted by Grace Cordovano to the USCDI, and explained that it was leveled at the Comment Level, meaning that it is less mature and had no applicable vocabulary standard or implementation guide (IG). He detailed its working definition, the background information, and reasoning for this item as a potential data element that could be added to USCDI in the future once it reaches sufficient maturity.

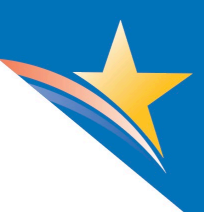
## **TOPIC: PRESENTATION: CLOSING DISABILITY DISPARITIES: EHR DATA AS THE FIRST STEP**

Arien welcomed the presenters from the disability rights community and discussed his personal and family experiences receiving disability care. He stated that there is no binary status related to disability; rather, it exists on a continuum and changes over time. He cautioned against categorizing these statuses as deficits and stated that everyone will experience these statuses at some point in their lives. He emphasized the need to describe the disability status of a patient clearly, accurately, and in a clinically descriptive manner to support and justify appropriate accommodations and care.

Arien introduced the presenters, Silvia Yee, BM, MA, LLB, Disability Rights Education and Defense Fund, Bonnielin Swenor, PhD, MPH, Johns Hopkins Disability Health Research Center, and Megan A. Morris, PhD, MPH, CCC-SLP, Disability Equity Collaborative. Bonnie introduced herself and her co-presenters. She recognized the complexities inherent in conversations around the broad disability community and emphasized the need for clarity in the terminology used to discuss and document disability and how and what related data are measured. She displayed the Disability Status, Functional Status, and Mental Status data class information (included in [the Documenting Disability presentation slide deck](#)), which included the goals and uses (medical construct vs. demographic/social construct) stemming from the inclusion of each. She noted for each data element whether the patient reports the information or if it comes from a clinical assessment. She described the role of social determinants of health (SDOH) on care and explained that one in four people have a disability, making this community the largest minority group in the United States. Bonnie described the significant health and healthcare disparities associated with disability and described how disability data gaps in electronic health records (EHRs) have limited the COVID-19 response. Bonnie emphasized the need to better measure disability data to ensure improvements to the quality of health and healthcare, the effects of equity interventions, and the provision of appropriate accommodations.

Megan described ways in which disability status is/is not documented in the EHR and spoke about support from patients. She stated that disability status has been identified as a top research and policy priority. She discussed challenges that health systems have encountered while struggling to implement system improvements, and described examples of legal requirements around documenting a patients' disability status and accommodation needs. She described her work with the [Disability Equity Collaborative](#), which she stated is the nation's leading organization providing evidence-based knowledge and practical solutions and tools to address the complex problems in disability access in healthcare. Megan added that over 50 members of the Collaborative have been working on improving the documentation of patient disability status, though most have not overcome the challenges. These members have identified the need for policies around standardizing the documentation of disability status in the EHR, and she explained that they are working with Epic to identify appropriate standards.

Megan shared a list of questions from the American Community Survey (ACS) and the Washington Group around seven categories of disabilities. She described the process they used to create this list of questions and emphasized that because disability status changes over time, the questions need to be asked and responses documented repeatedly. Also, she shared recommended future question categories, which



included learning disability, mental health disability, autism/social disability, health care accommodations (provided within the healthcare setting), and caregiver information related to their own disability status.

Silvia explained that there are no perfect disability questions because it is a socially constructed concept, and the physical, social, cultural environment in which healthcare takes place has never been captured well and cannot be captured without demographic data on functional limitation. She added that not everyone with an impairment will identify as having a disability and that language related to disabilities also changes over time and is affected by culture. She emphasized that, despite these challenges, people with disabilities cannot wait any longer. She shared an extensive list of reasons for urgency, which was included in the presentation slide deck, and she described specific use cases related to each of the reasons. She presented four recommended action steps, which included:

- Include Washington Group and ACS disability questions as a component of Demographic data within the EHR
- Ensure that a patient-reported data collection approach is used
- Recognize this is a first step. Future efforts should focus on accommodations
- Support the use of disability data to improve clinical care and address healthcare inequities

### **TOPIC: PRESENTATION: CAPTURING FUNCTIONAL DISABILITY AND COGNITIVE STATUS USING ICF**

Arien introduced Matt Elrod, PT, DPT, Med, MaxMD, who presented an informatics-based view of capturing functional disability and cognitive status. Matt introduced himself and provided background information. He explained that the World Health Organization (WHO) has a family of International Classifications and Terminologies that includes the International Classification of Functioning, Disability, and Health (ICF) Framework, and he described the clinical uses of the ICF, which were detailed in [his Health Status presentation slide deck](#). Matt shared his experiences and use cases from his work as a physical therapist to illustrate the usefulness of the ICF. He displayed a depiction of the interaction and interdependencies between the concepts (patient's health conditions, body functions and structures, activities/limitations, participation/restrictions, environmental factors, and personal factors). He discussed the hierarchical structure and various chapters of the components used to describe how someone is moving around and functioning in their environment. He highlighted Chapter 4: Mobility, 4500 Walking short distance through the use case of a patient who previously had limited shoulder functionality and then was hospitalized with COVID-19, resulting in additional changes to his mobility. He stated that this information is not dependent on any single, specific standardized test or measure and agreed with the previous presenter's statement that there is no perfect set of questions that address all patients, though the ICF provides a common standardized construct to share like concepts.

Matt discussed how the ICF Framework relates to the draft USCDI v3. He explained that ICF is used to operationally define a person's health and that the health-related states and that the terms and construct are person-centric. The ICF is widely used by the rehabilitation community and is supported by the payer and clinical community with multiple standard assessment tools. Through this mapping, it supports both "Functioning" and "Disability." He described how the hierarchical structure of the ICF classifications of Function and Disability could be rolled up to help share meaningful information, regardless of where someone is in the continuum of care. He discussed similarities between how SDOH and ICF terminologies can be used to represent multiple data classes.

Matt shared recommendations for the alignment of ICF and draft USCDI v3 and recommendations for using a similar approach of data elements in various data classes as has been used with SDOH. All of these recommendations were detailed in the presentation slide deck.

### **TOPIC: PRESENTATION: PROPOSALS: HEALTH CONCERNS AND HEALTH STATUS ASSESSMENTS DATA CLASSES**

Arien introduced Holly Miller, MD, MBA, FHIMSS, and Terry O'Malley, MD, who presented a series of



observations and recommendations regarding the Health Concerns and Health Status Assessments data classes. Terry summarized their recommendations; Holly shared supporting details. Their proposals were laid out in their [Health Concerns and Health Status Assessments Data Classes presentation slide deck](#) and included:

- Keep Health Concerns as a separate data class as in USCDI v2
  - Terry recommended that the ONC should not subsume this under Health Status in USCDI v3, because Health Concerns represent a different concept that is related to but separate from Health Status and Problems
  - Holly commented that Health Concerns could indicate that further evaluations/workups are necessary for the patient.
- Rename “Health Status” data class as “Health Status/Assessments”
  - Terry stated that, currently, no data class in USCDI easily accommodates the results of standardized assessments. He stated that Assessments are the mechanism by which a Health Concern becomes a Health Status. He discussed the confusion around the use of the existing data class of “Assessment and Plan of Treatment.”
  - Holly explained that they recommend that ONC clearly differentiate between the Assessment & Plan of Treatment utilized in traditional Subject, Objective, Assessment, and Plan (SOAP) clinician notes (where Assessment is usually indicates an impression or diagnosis) and the many formal Assessments that are utilized to document Health Status.
- Propose a definition for “Health Status / Assessments” and discuss the relationships between “Problems,” “Health Concerns,” and “Health Status / Assessments”
  - Terry explained that the connection between these data classes is dynamic and described how they are closely related, yet separate. He described the use case of pregnancy when describing how an Assessment may resolve or create a Health Concern; and it may create or resolve a problem. A Problem may become a Health Concern and vice versa. Each data class serves a distinct purpose in clinical documentation.
- Propose content for the “Health Status/Assessments” data class
  - Terry presented recommendations and proposed content items for USCDI v3, which were detailed in the presentation slides. These included expanding Functional Status, recommendations around Functional Status Assessments, expanding Mental Status, expanding SDOH, and adding Immunization Status.
  - Holly highlighted how expanding Functional Status could improve transitions of care.

## TOPIC: Q&A ON PRESENTATIONS

The IS WG co-chairs thanked the presenters and invited WG members to submit feedback and questions on the presentations. Arien shared comments from the chat and invited WG members to share verbally.

### DISCUSSION:

- Hans thanked the panelists and submitted the following comments:
  - Consider the following: could the Health Status/Assessments” data class be split, and then all assessments-related data elements could be combined into one data class?
  - Terry responded that all assessments-related elements could be moved into one data class, which would leave Plans of Care and Treatment Plans. The class could then be repurposed.
- Steven acknowledged the rich discussion underway in the public Zoom chat and highlighted a discussion around whether the Disability Status or Functional Limitations data elements belong in this new health status data class or whether they would better be suited to Demographics. He reminded WG members that these are data that are already being collected, so standardizing them could improve care, but that there could also be unintended consequences. He explained that including them in the USCDI is important to standardize data, and in which Data Class they are included is relatively less important.



- Arien asked the first panel to comment on how to best balance collecting data to improve health outcomes and advocacy versus the risk of future discrimination and unintended consequences.
  - Silvia stated that technical protections could be put in place (artificial intelligence, algorithms), but she stated that in the present state, without this information/capturing the data, discrimination is already happening. Arien summarized by observing that more harm is done by not collecting data.



- Clem commented in support of Terry's explanations around the differences between Assessments (survey instrument and data that have been verified and validated) and Plan of Treatment. However, he disagreed with the recommendation to separate Concerns from Problems and discussed challenges related to maintaining these lists. Arien responded that Health Concerns already exists within the USCDI and is not part of the IS WG's current charge.
- David asked the panelist to comment on the adequacy of a simple structured assessment as a starting point for capturing this data. He complimented the example assessments that were shared but asked if they are adequate for capturing all the recommended data. Should structured assessments be used as a starting point, with text to be added as appropriate?
  - Terry commented that structured assessments are adequate and that there are thousands that are validated and standardized. Steven highlighted Al's comments in the public chat that ONC has already done this within the data class. He highlighted work done previously on identifying specific LOINC-coded instruments that could be used with SDOH Assessments. ONC has the option of including that level of specificity regarding these assessments in the USCDI v3 specification. Holly agreed that this then makes them codifiable and more interoperable as patients transition.
- Alexis submitted the following comments:
  - She expressed concern over including Assessments in Health Status data class, because not all assessments (standardized assessments or a provider's assessment of the situation without using a standardized test) will classify a diagnosis or health status. She described ways in which patients might be disqualified from benefits or services before their diagnoses are officially diagnosed.
  - She was concerned about saying that a patient's concern is not an actual problem, noting that this subjectivity could increase discrimination.
- Grace asked if work that has been done on Social Security disability benefits could be added to enhance conversations around Health Status, Disability Status, and Functional Status.
  - Arien agreed and stated that this work will likely be reviewed through the new USCDI+ initiative. An IG was previously published for C-CDA-based data that includes the full documentation required for public disability determination.
- Ike commented that both unstructured and structured data are needed to account for assessments for patients with certain rare conditions and to share assessment information across their care teams. Flexibility and structure would both be important to capture and categorize information over time.
  - Arien agreed and commented that the discussion is generally related to pairing one or more LOINC codes with a data element. This overall concept can support both structured assessments and questionnaires, as well as unstructured observations and patient self-assessments.
- Mark thanked all the presenters and submitted the following comments:
  - He is glad that the WG and ONC staff will be reviewing the important comments in the public Zoom chat.
  - The first presentation emphasized the importance of self-reporting for capturing disability status, and he asked if the ICF alignment could also be used for self-reporting. Matt responded that ICF is used for both self-reporting, as well as clinical observations.
- Clem responded to Terry's comments on the thousands of quantitative survey instruments and encouraged that ONC specify only those that are validated. If there are too many surveys or they are too long, comparison becomes difficult. A short list of applicable surveys should be highlighted as part of specifying USCDI data elements.
  - Arien agreed and noted that the first panel recommended that the ACS Washington survey is the best one to use.



## Action Items and Next Steps

IS WG members were asked to capture their thoughts and recommendations between meetings in two Google documents that will inform the WG's recommendations and streamline the conversations. Members should share a Google email address with ONC's logistics contractor at [onc-hitac@accelsolutionsllc.com](mailto:onc-hitac@accelsolutionsllc.com) to be set up with access to the document. Once WG members have gained access, they may input recommendations and/or comments into the appropriate documents:

- IS WG Member recommendations regarding Draft USCDI v3 and Level 2 Data Elements (members have full edit access to this document)
- Draft USCDI v3 data elements sheet for recommendations on changing or removing data elements (charge 1a) (members may add comments but may not add lines), and consider these questions:

IS WG members will be prepared to engage in conversations with presenters to better inform the WG recommendations. WG members may enter comments on this topic into the Google documents to keep track of individual thoughts.

- For homework for the March 8, 2022, meeting:
  - AI will extract specific recommendations from each speaker's presentations and enter them onto the IS WG Draft USCDI v3 Member Recommendations (Editable) Google doc, so there is no need for anyone else to capture this information.
  - In order to capture WG members' other recommendations related to the Health Status data class, members should log into the IS WG Draft USCDI v3 Member Recommendations (Editable) Google doc and enter them.
  - In the next and upcoming WG meetings, the WG will focus on the Draft v3 Data Elements for ISWG Review google doc, including a review of the work Hans has done determining the extent to which the Draft USCDI v3 new data elements are represented in FHIR (including US Core) and C-CDA IGs. WG member will review this spreadsheet, enter comments as appropriate, and be prepared to discuss at the next meeting.
  - The self-imposed deadline for WG members' input into both spreadsheets is Friday, March 18, and members were asked to not wait until the last minute to provide input. The WG will work through the submitted suggestions and comments over the next several weeks, shape them into recommendations from the WG as a whole, and consider assigning priorities to them. We are already pushing 50 discrete workgroup member recommendations, so will probably have to prioritize and/or trim the overall list down.
  - The WG will work through the spreadsheet over the next three meetings, reserving the March 29, 2022, meeting for the recommendations that will come in that week, followed by prepping the recommendations transmittal for review and finalization by the WG on April 5, 2022. The WG needs to deliver the recommendations letter to the HITAC co-chairs the week of April 4, 2022.
- Members are invited to consider more ideas on the WG's Task 2 work on the Interoperability Standards Advisory (ISA) Standards, which should start in early April 2022, following the completion of the WG's Task 1 recommendations to the HITAC. ISA related topics to consider
  - TEFCA standards enablement
  - FHIR roadmap, standards from FAST, patient access leveraging QHINs for national access
  - Additional exchange purposes that are contemplated in CURES but not perfectly enabled via initial TEFCA
  - Potential standards/IGs for HIE certification
  - Social Determinants of Health (SDOH) / Gravity data standards
  - Race/Ethnicity vocabulary subsets, e.g., CDC
  - Lab Orders/Results
  - SHIELD/LIVD, LIS to EHR/PH SYSTEMS





- Public Health (PH) data standards and potential PH Data Systems Certification
- eCR Standards
- Other ISA topics of interest

## Public Comment

### QUESTIONS AND COMMENTS RECEIVED VERBALLY

There was one public comment received verbally:

Michelle Dougherty: My name is Michelle Dougherty, thank you. I'm a senior health informaticist with RTI International. My background includes 15 years of experience 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. So 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 Draft v3 for Mental Status and aligns with the Functional Status proposal currently in Draft 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 the consideration by the workgroup for their recommendations. Second, just to support Dr. O'Malley and Dr. Miller's 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 areas in trying to differentiate between Observations versus Problems, I just wanted to note that I felt agreement with their recommendation that Health status is more aligned with Problems, and, therefore, perhaps not part of this heading. And, I understand the limitations as well. Then I'm also in agreement with SDOH items, which are often based on screens and status information, and, potentially, there's some better alignment in the Health Status / Assessments class that's being discussed today. Also, I'd like to address a comment that came in today around the current Assessment and Plan of Treatment data class/element. I would like to express my support for updating that naming to something that was brought out here today as "Plans and Treatments." So, for example, that could address care plans, it could address treatment plans and orders, areas that are gaps that we know to identify in our analysis of USCDI and the current classes that have been submitted. 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's a FHIR accelerator workgroup, and as well, I work on the CMS Data Element Library and Health IT workgroup. As part of the team that's supporting the development and evolution of the Functional and Mental Status FHIR implementation guides, we've worked with the FHIR workgroup and community meetings, and we hit challenges that were really significant regarding 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. But 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. So, I wanted to share that experience and how it helped bring consensus to the workgroup and a path for the future.

### QUESTIONS AND COMMENTS RECEIVED VIA ZOOM WEBINAR CHAT

Michael Berry: Good morning everyone. Thank you for joining the Interoperability Standards Workgroup. Please remember to set you chat to "Everyone" so that everyone can read your comments. Thanks!

Steven "Ike" Eichner: One of the issues the Work Group should be sensitive to, especially with regards to disability status, are ensuring any recommendation recognizes the variety of the abilities of individuals with disabling conditions and does NOT combine the nature of any limited functionality resulting from a health condition.

Steven Lane: Thanks Ike.



Clem McDonald: Sorry, I am late but now I am here , Clem

Grace Cordovano: I'm wondering if something like an individualized education plan (IEP) could serve as an example of standardized information that could provide critical accommodations *[sic]* information?

Steven "Ike" Eichner: Grace: Yes, however FERPA would apply. Sharing the document/information would require consent.

Alexis Snyder: Plus + to Ike's comment, and re: grace's comment-504's as well

Yomi Wrong: Accommodation needs change over time for PWD, so any documentation tool should not be static

Alexis Snyder: Agreed, how and when to update is needed

Steven Lane: Great comments here about Accommodations. Recall that this is NOT a Level 2 data element so will not be available for specific inclusion in USCDI v3. Nore *[sic]* work on this data element will help to prepare it for future inclusion.

Steven "Ike" Eichner: I have significant mobility limitations resulting from a progressive condition that results in my muscles transforming into bone. As more muscles transform, there is an increasing tax on my independence.

The condition does NOT impact mental functions/mental capacity.

I can't tell you the number of times I have been treated as though I have exceedingly limited mental capacity. My wife is usually asked what I want for dinner when we go out for dinner. Segregating information across the nature of the functional limitation is critical in describing the limitation, evaluating the functionality, communicating needs, providing any accommodation, treating/addressing the underlying condition, if possible, measuring functional change, and other uses.

Alexis Snyder: All 4 of those people in the graphic could have a disability that we can't see

Arien Malec: It's remarkable that when this topic is introduced we discover how many of us live on this continuum or are personally touched by disability.

Michael Berry: The recording for today's meeting along with the presentation materials can be found here: <https://www.healthit.gov/hitac/events/interoperability-standards-workgroup-4> The recording should be available later today.

Grace Cordovano: Wonderful to hear @Megan emphasize that individuals *[sic]* DO want and expect discussions and support for their disability status. From my patient advocacy work, individuals living with disabilities find it incredibly frustrating and harmful when they need to continue to repeat their stories bc data is not adequately documented, captured, shared, and made actionable.

Alexis Snyder: What defines "serious" this language needs to change

Carolyn Petersen: It's true that we can't improve what we don't measure -- but measuring these things also facilitates discrimination by providers and health systems. As standards are developed we also need work to ensure that standards work done to reduce disparities is widely adopted and implemented in ways that actually improve the health outcomes and thus lives of people with disabilities.

Clem McDonald: This set of questions is GREAT. All of the areas of current interest end up needing a survey instrument to capture them. However there is often many , sometimes a hoard of questionnaires *[sic]* and we should choose one if possible for a give purpose to make the data most useful. There are not informatics



challenges to the capture and structuring of survey instrument [sic] FHIR and V2 already have structures that accommodate them. Think the questionnaires [sic] just presented to should be praised. It short will not overload the practice setting and gets to the many possible definitions of disability well.

Grace Cordovano: Many healthcare delivery organizations, hospitals, cancer centers, imaging centers, and physicians offices implemented COVID19 No Visitor Policies, separating patients from their carepartners and support persons. There was significant harm and trauma inflicted upon patients as a result of the fact that we do not capture the very information that is so eloquently presented here. I'm hopeful that we can fill many major gaps by the work being led in this space and through our WG recommendations.

Arien Malec: Reminder to set your "To:" to "Everyone" to make sure your comments are in the public record.

Steven "Ike" Eichner: Hospital issues are not limited to individuals with cognitive limitations. It has also impacting individuals with mobility limitations/paralysis.

David McCallie: One concern is that capturing these structured measurements could take time away from already too short clinical encounters. Will there be additional reimbursement for additional staffing and/or encounter time to avoid squeezing out time for other clinical concerns?

Megan A. Morris: These are patient reported questions that could be asked as a part of scheduling, rooming, patient intake forms, registration, patient portal, etc. It does not need to be asked by a clinician. Disability status and accommodation needs should be asked early in care so the team can provide accommodations in a timely and efficient manner.

Alexis Snyder: Agreed

Grace Cordovano: Thank you for an exceptional presentation!

Mark Savage: Wow! Thank you so much Bonnie, Megan, and Silvia.

Arien Malec: @David - including a slot != requiring documentation in all encounters

Arien Malec: Thanks to Silvia, Bonnie & Megan for an amazing presentation!

Steven Lane: USCDI provides the containers into which this data is put and must be exchanged IF available. The "must" only occurs through future rulemaking.

David McCallie: @Arien - that's an important clarification - what is the expected impact of including broad (new) categories into USCDI. Do they become "required" in common practice? That seems to be the goal here, at least in part.

Arien Malec: The goal here is to make sure that when data are captured they are interoperable and appropriately structured.

Silvia Yee (she/her(s)) DREDF: @Steven Eichner, I absolutely agree that hospital issues extended to people with various disabilities, including those with mobility limitations, vision, hearing and various other functional limitations. Inaccessible restrooms and examination and diagnostic equipment and spaces that don't allow wheelchairs to turn around place people with mobility disabilities in situations where they can be subjected to unsafe transfers or provider biases about their quality of life. Individuals with vision and hearing limitations were deeply afraid of being very ill in a hospital and unable to "typically" see or respond to providers who were using visual or spoken testing for consciousness or the ability to improve with treatment. Any given diagnoses does not always capture the specific degree of a patient's functional limitations.

Mark Savage: Thank you, Matt!



Steven "Ike" Eichner: The diagnosis of my condition (like a number of other conditions) does not reflect the functional status of anyone with the condition.

Carolyn Petersen: +1 to Steven's point of not specifying instruments

Alexis Snyder: +2

Arien Malec: In general, we are talking about LOINC code + value, in an organized container.

Steven Lane: I meant to say that we CAN identify instruments and which data class they belong in, but that such specification does not constitute a requirement for utilization.

David McCallie: We shouldn't specify instruments, but it is crucial to specify a standard way to represent and share the chosen instruments. Just like we do for lab tests, medications, immunizations, etc

Arien Malec: Depending on the LOINC code we use we can represent a Washington questionnaire, patient self-assessment, etc.

Arien Malec: can.

Megan A. Morris: The ACS and Washington Group questions are coded within LOINC 2.71

Arien Malec: A reminder that USCDI is \*not\* about the EHR workflow, but the slots against which interoperability is defined.

Jim Jirjis: Reminds me a little of family history collection...no shortage of ability to design a multi-step process to capture family history (who has what and with what confidence) but the clinicians do not have time to sit down and do this so it has not generally taken off

David McCallie: But slots create expectations, and ....

Steven Lane: We have a slot for height, but that does not mean that it is collected at every visit. If it is collected, however, we know where it goes for interoperability.

Jim Jirjis: Seems like certain specialties that focus on such assessments would use this but others may have trouble having time

Matt Elrod: While ICF has codes that can be used for all levels of the hierarchical structure, there are LOINC codes for ICF components and chapters. <https://loinc.org/search/?t=1&s=ICF>

Steven "Ike" Eichner: One difficulty is "assessment" is how to address things like physical therapists' assessment of range of motion. How does that type of test "fit in?"

Alexis Snyder: Standardized tests do not capture all dx's for health status

Steven "Ike" Eichner: how to.

David McCallie: Keep separate what "ought" to be captured from "how" it's captured and "where" it slots into an interoperability process

Steven Lane: This presentation is a great example of how the USCDI can evolve over time to more logically organize and represent the core data to support interoperability and hence care.

Steven "Ike" Eichner: Vision is another concept that may be fluid.



Steven Lane: Also note that the Data Class where a specific Data Element is placed does not significantly impact whether/how the data can be accessed, exchanged and/or used.

Hans Buitendijk: If Health Status is renamed to Health Status/Assessment, how would that impact Assessment and Plan of Treatment data class? Would you suggest to split that and only focus on Plan of Treatment as forward looking while an assessment represents a current state set of one or more observations?

Steven "Ike" Eichner: "eligible" for an immunization is a concerning label.

Arien Malec: @Hans — I had the same thoughts.

Mark Savage: Can Terry and Holly speak to what "expand SDOH Assessments" means?

Grace Cordovano: There's great emphasis on patient contributed/reported information in this arena. I'm trying to see there are more standardized pieces of information that are readily available that may support the data proposed for v3, for example, would linking Social Security Disability Benefits if an individual is a recipient be helpful to consider for inclusion?

Arien Malec: I \*think\* there's a lot of mileage we can get by having a range of LOINC code + output of questionnaire/assessment. *[sic]*

David McCallie: Expanding the assessments should be value set problem, not creating new slots in USCDI. As assessments evolve, they can still be exchanged in these high-level categories (slots)

Donna Doneski: Isn't "Assessment & Plan of Care" using assessment as more a term of art whereas assessments (as a noun) refers to tools that capture data already?

Steven Lane: +1 Donna

Steven "Ike" Eichner: By age, gender, or other base characteristics I might be "eligible" for a vaccination, but there may not be a vaccine that is compatible with my underlying biology.

David McCallie: We don't enumerate every lab test that could be exchanged, but rather we specify a standard way to exchange any lab test. Substitute "assessment" for "lab test"

Al Taylor: Ike i wanted to point out that ONC already certified to Immunization forecasting, which applies decision support to immunization history to make recommendations for further immunizations/vaccines.

Alexis Snyder: Not all dx "status" can be captured by assessments *[sic]* and labs

Matt Elrod: Why would the "assessment" as a standardized test not be a clinical test?

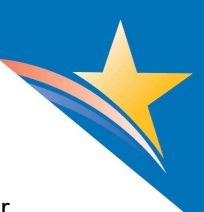
Jim Jirjis: Why can't everyone be set as the default so each call we do not run into this

Clem McDonald: Think that Terrys distinction between physician's plan and ASSEENET. *[sic]* Agree that is just summary of his/her thinking and not the same as measured assessments. Agree 100%

Steven "Ike" Eichner: I am generally willing to provide information regarding *[sic]* my condition to my health care team. My concern is being "lumped" into too broad a class.

Bonnielin Swenor: We do more harm by not collecting this data.

Steven "Ike" Eichner: One of the standardized functional assessment questions that bothers me is whether I can get my wallet out of my back pocket. Last year, I could get it out of my right pocket. I haven't been able to



reach my back left pocket for 35 years. The assessment question isn't detailed enough. It doesn't clarify either pocket, or two questions, one for each pocket. And understanding each arm's mobility may be important!

Hans Buitendijk: @Matt Ellrod: You are raising an interesting question whether assessments could be clinical tests. In the standards being contemplated (C-CDA and FHIR in particular, but HL7 v2 as well), these all are typically done as observations or profiling thereof. This is will continue to be a balancing between the common clinical and business terminology that yields typically more splitting, vs. information management where like concepts can be managed together. PACIO profiles functional status from an observation. Likewise, assessments and clinical tests all end up being profiled from observations.

Michelle Dougherty: Concur with Matt's comment to consider standardized assessments is observation data

Alexis Snyder: And again, observation does not always align with health status

Carolyn Petersen: While the things suggested in the presentations may take us some way toward better documenting disability, they may not get at the lived implications of the individual -- and thus fail to signal to the clinician what can be addressed via medicine. For example, fragrance sensitivity is a common late effect of cancer treatment, and the way some people with this sensitivity manage it is by avoiding situations in which they are around others who may wear fragrance, i.e., no dining out, theaters, or other social events. Simply capturing that an individual has this sensitivity doesn't convey to clinicians that the individual may lack a social network, may not be able to achieve the prescribed level of activity, etc. Working to capture this "implication" info, as well as other info, is critical for the success of these efforts related to disability.

Grace Cordovano: +1 Carolyn....also goes for no tuna salad in the infusion suite

Alexis Snyder: Plus 1 to Carolyn

Matt Elrod: @Hans: The ICF offers an ability to use standardized test and measures and organize concepts of Functioning (Mobility and mental status)

David McCallie: @matt - is the ICF open or proprietary?

Steven Lane: +1 Carolyn. Great point re how it may be difficult to express Patient Concerns using the Problem List. In this case ICD-10 does not provide the required specificity to express fragrance sensitivity: <https://www.icd10data.com/ICD10CM/Codes/R00-R99/R40-R46/R43->

Silvia Yee (she/her(s)) DREDF: While I appreciate that social security is a well-established "disability" information system, it is also a system that is rooted in employment income replacement and inherently includes a degree of "gatekeeping" that is not necessarily appropriate to the purpose of including disability elements in USCDI, or at least, does not fully capture reasons for having disability status information. SS information leans toward assessing significant disabilities that affect employment and that will not lay the groundwork for capturing the accommodation needs that will allow patients with various disabilities and degrees of functional limitation to receive equally effective healthcare.

Matt Elrod: ICF is as ICD. Both from WHO. The licensed use of the codes would follow the same as ICD 10.

Steven "Ike" Eichner: I think there's a need for both structured and unstructured data.

Supporting an unstructured data element would support individuals with rare conditions

Carolyn Petersen: Re: discrimination, yes, there are laws that are supposed to protect individuals. However, compliance with these measures is inconsistent, and those who experience harm often lack the resources/skills to achieve redress. I will reiterate -- we can't fix what we don't measure, but individuals require protection from the harms that are facilitated through data collection.



Steven Lane: At this point we have the opportunity to advance data elements that COULD include structured data/instruments but that would not EXCLUDE using the same data element from carrying unstructured/textual data.

Michelle Dougherty: Sharing my public comments via chat: • Public Comments: My name is Michelle Dougherty, Sr. Health Informaticist with RTI International. My background which includes 15 years of experience advancing interoperability to support aging and disabled populations, identifying gaps in interoperable data classes, and proposing 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 gaps in early iterations of the Common Core Data for Interoperability, proposed data and standards that are included in the Interoperability Standards Advisory, and proposed the functioning data class that is currently referenced in V3 for mental status and aligns with the Functional Status proposal by Dr. Miller.

Michelle Dougherty:

- Appreciation for the expertise and recommendations of all presenters to inform this important data class for consideration by the workgroup.
- Support for Dr. O'Malley and Dr. Miller's presentation and proposal for the data class to be renamed to focus on "Health Status/Assessments"
- Agreement that health concern is more aligned with the problem data class rather than health status; and also agreement that the SDOH items which are often based on screening and status information is better aligned with the Health Status/Assessments class proposed.
- A recommendation that the current Assessment and Plan of Treatment data class be updated to reflect "Plans and Treatments" which could include care plans and treatment plans/orders.

Steven Lane: Thanks @ Michelle - Very helpful!

Michelle Dougherty:

- Endorsement of the International Classification of Functioning, Disability and Health (ICF) as an organizing framework as presented by Matt Elrod. In working with the PACIO Project FHIR Workgroup and CMS Data Element Library Health IT Workgroup, I am part of a team supporting the development and evolution of the Functional and Cognitive Status FHIR Implementation Guides. FHIR workgroup/community meetings had been challenging as there were significant differences of opinion based on clinical expertise when discussing types of data these IGs should cover and how they should be expanded over time. ICF provided a credible, well-researched organizing structure for the IG and future expansion – it has helped bring consensus to the workgroups. Of note, ACS and Washington Group identified 7 Questions in their presentation– they are important and a number of the questions are including in the FHIR IGs for functional status.

Bonnielin Swenor: However using SS to identify people with disabilities is flawed due to the barriers to enrollment. The concern is that using enrollment in these programs to determine disability leads to a selection bias.

Michelle Dougherty:

- Suggestions for future work of the ONC HITAC Interoperability Workgroup focusing on two complex standards that have the potential for significant impact –Transitions of Care (TOC) and eCare Plans. There have been foundational work completed on data, standards, and testing, but complexities bringing together different data classes (particularly with TOC), understanding the data needs of the receiver or data limitations of the sender, and other unique issues will benefit from the leadership and expertise of this group.

Arien Malec: Thank you @Michelle — both these comments and your email comments will be part of the public record.

Steven "Ike" Eichner: The companion to the LOINC code might be some education, especially for the rare disease community.



Silvia Yee (she/her(s)) DREDF: @Carolyn Petersen, I absolutely agree that strong data protections are necessary, across all provider types, entities, and governments.

David McCallie: @Clem - you don't want ONC to pick your lab tests do you 😊

Carolyn Petersen: One thing to bear in mind -- the people who've been discriminated against may not respond to surveys about how important it is to collect data, because they've learned that responding only worsens their situation

Silvia Yee (she/her(s)) DREDF: While we did not have the time to go into our Appendix, there is very useful information there about how the WG and ACS disability questions are validated. WG questions have been validated cross-culturally as well.

Matt Elrod: ICF offers a way to bring concepts together regardless of the standardized test used

Mark Savage: THANK YOU to today's presenters for your time and expertise!

## **QUESTIONS AND COMMENTS RECEIVED VIA EMAIL**

There were no public comments received via email.

## **Resources**

[IS WG Webpage](#)

[IS WG – March 1, 2022 Meeting Webpage](#)

[IS WG – March 1, 2022 Meeting Agenda](#)

[IS WG – March 1, 2022 Meeting Slides](#)

[HITAC Calendar Webpage](#)

## **Meeting Schedule and Adjournment**

Steven and Arien thanked everyone for their participation and shared a list of upcoming IS WG meetings. The co-chairs will take the recommendations and output from the panel presentations and will turn them into WG recommendations.

The meeting was adjourned at 12:02 p.m. E.T.