Massachusetts Health Data Consortium

NCVHS ICD-11 RFI 2 Comment

This document is submitted by the Massachusetts Health Data Consortium (MHDC) and its Data Governance Collaborative (DGC) in response to the second NCVHS ICD-11 RFI posted in the Federal Register on October 16, 2023 and found here: https://www.federalregister.gov/documents/2023/10/16/2023-22753/national-committee-on-vital-and-health-statistics

About MHDC

Founded in 1978, MHDC, a not-for-profit corporation, convenes the Massachusetts's health information community in advancing multi-stakeholder health data collaborations. MHDC's members include payers, providers, industry associations, state and federal agencies, technology and services companies, and consumers. The Consortium is the oldest organization of its kind in the country.

MHDC provides a variety of services to its members including educational and networking opportunities, analytics services on both the administrative and clinical side (Spotlight), and data governance and standardization efforts for both clinical and administrative data (the Data Governance Collaborative/DGC and the New England Healthcare Exchange Network, respectively).

About DGC

The DGC is a collaboration between payer and provider organizations convened to discuss, design, and implement data sharing and interoperability among payers, providers, patients/members, and other interested parties who need health data. It is a one stop interoperability resource. The DGC primarily focuses on three areas:

1. Collaboration: Development of common understanding of and specifications for data standards, exchange mechanisms, and what it means to participate in the modern health IT ecosystem
2. Education: helping members understand their regulatory obligations, the data and exchange standards they're expected to use, and modern technology and related processes
3. Innovation: Identification and development of projects and services needed to make modern health data practices and exchange a reality

MHDC History with ICD-9 => ICD-10 Transition

This section describes the Massachusetts-wide ICD-10 testing project run by MHDC and discusses how we think our experiences can help prepare for and improve the process of moving the healthcare community to ICD-11.

About the Project

Starting in 2012 and running through the official industry adoption date for ICD-10, MHDC ran a Massachusetts-wide universal ICD-10 testing platform for payers and providers across the state. In addition to MHDC serving as the overall project manager, the project management team included the Massachusetts eHealth Collaborative (MAeHC) to assist with provider integrations and a national vendor to assist with payer integrations.

The project had three primary goals:

1. Making sure that small providers and payers had the same access to testing as their larger

counterparts

2. Making sure the end-to-end workflows work
3. Helping folks be ready to transition on time

Overall, the project was a great success and we met these goals. 92 organizations participated in the testing including nearly every payer in Massachusetts, nearly all hospitals in Massachusetts (including behavioral health institutions), and several large provider groups. While smaller providers were given equal access, few of them took advantage of it, often citing lack of resources as the reason they did not participate.

Scope of Project

Some of the key choices made around the scope of the project and use of ICD-10 codes included:

1. ICD-10 would be used for new coding only, no attempt to migrate ICD-9 codes would be made and thus no such migrations would be tested. This was primarily because of the difference in definitional granularity/specificity between the two code sets and the inability to determine a consistent, straightforward way to map many ICD-9 codes to a single, clearly equivalent ICD-10 code.
2. This project was for connectivity testing only. The expectation was that each organization would independently do whatever work they needed to do to support ICD-10 within their internal systems and to support sending or receiving codes in that format. Only once that work was completed would an organization be considered ready to start interacting within the community test platform.
3. The project focused solely on the claims cycle and clarified the administrative and financial role of ICD codes versus other code sets like SNOMED. In keeping with this, no attempt was made to look at conversions or mappings between ICD-10 and any of the clinical code sets commonly in use by providers.

Lesson Learned 1: Benefits of Joint Testing Extended Beyond Scope of Project

While the scope of the testing project was limited to the connectivity between trading partners, we found the benefits of joint testing extended well beyond that. In particular, the project provided a forum for airing out challenges organizations ran into within their black boxes, turning to the community to help them solve those problems, and learning how others dealt with the same or similar issues.

Lesson Learned 2: Testing for Revenue and Payment Integrity Not Feasible

The biggest ask/concern from participants early in the project was assessing the impact of switching to ICD-10 on their revenue (for providers) or on payment integrity (for payers). We determined that it was not feasible to try to address these concerns in any realistic way for several reasons:

- It was too difficult to create realistic test data for a wide variety of scenarios
- It was too difficult to fully replicate entire payer systems in the test environments, meaning some potential components of the revenue cycle were not applied
- It was too difficult and too time consuming to run every possible scenario across every possible pair of exchange partners

Lesson Learned 3: Focus on Codes Used Already Not the Full Scope

In general, familiar codes were given preference by providers and the smallest changes possible were usually implemented rather than trying to find some completely new solution even if it fit slightly better. Thus, only a subset of ICD-10 codes that most closely matched the ICD-9 codes already in place were used and tested.

In addition to reducing the work on both implementation and testing to a more manageable size, this also meant organizations focused on the most useful components of ICD-10 and did not have to worry about issues, incompatibilities, or how to map ICD-9 codes they were already using to more complex ICD-10 codes that might capture more information but required adjustments to existing workflows and provider practices.

Lesson Learned 4: In General, Providers Ready Before Payers

In general, the lift for moving from ICD-9 to ICD-10 was heavier for payers than providers and it took them longer to complete their internal work in preparation for connectivity testing. This caused some churn with providers who were ready and chomping at the bit to start testing before their partners were ready to make the necessary connections.

Lesson Learned 5: Everyone Needed to Be Ready to Test Before Anyone Could Finish Testing

The project involved individual testing pairs between each organization and all of its trading partners. This meant that no matter how fast a particular organization was ready to test, it could not complete its participation until the last of its trading partners was also ready.

This caused some resentment, but it also meant organizations had difficulty budgeting how long and how many ICD-10 resources they'd need because there was no clear, set timeframe and the readiness of various organizations was staggered. This was an issue for everyone, but was particularly difficult for providers waiting for payers as they tended to be ready sooner (as noted above).

Additional Concerns Raised by Participants

Some additional concerns that were raised by participants throughout the project include:

- Payers were particularly concerned about impacts on risk adjustment and population health programs
- There was quite a bit of discussion around the need for education around the alignment between ICD-10 and DSM; it will be important to address this for ICD-11
- The need for clinical documentation specialists quadrupled in provider organizations to allow for updating of codes and this really hurt smaller providers. These specialists were needed to bridge the gap between the technology and the clinical workflows to limit clinician disruptions/changes to the physician experience.
- People didn't know how to search for codes, were unsure about how to apply new codes, or needed to augment documentation with secondary codes that weren't needed before which all caused churn.

Overall Takeaways from the Project

The high level takeaways from the project include:

- It was successful. The entire community switched to the new codes on the required day.
- it was less disruptive than expected.
- Don't make it more complicated than you have to; it was better to focus on a minimal viable set of interoperability testing.
- Make sure the transactions work, that's the basis for everything else.
- Don't invest in revenue/payment integrity testing.

General Comments

This section includes general comments on ICD-11 or comments on items that cross multiple questions in the RFIs.

Timeframe for Comment and Flexibility of Responses

We wish to thank NCVHS for providing a longer comment period on this RFI compared to the first ICD-11 RFI. We also appreciate the opportunity to respond to the questions from the previous RFI we were unable to address last summer in addition to the questions in the new RFI.

Timing of ICD-11 Adoption

Participants in our Data Governance Collaborative strongly urge that any required US adoption of ICD-11 codes be carefully scheduled around other major regulatory requirements, particularly major interoperability rules from CMS and ONC or the upcoming changes to race and ethnicity data proposed by OMB. Each of these regulations comes with a significant lift and requires a major commitment of organizational resources to meet. It is extremely difficult to comply when multiple major updates or new functionality are required at the same time.

Code vs Segment vs Other Terminology

As ICD-11 has a compound code structure, it is important to be clear whether an entire composite code or a segment of the overall code is being referenced in any discussions, presentations, or written materials. In various presentations by NCVHS, NIH, and others, the term “code” has often used both for the entire composite value and for a single segment therein. We strongly recommend defining consistent usage expectations with different words representing the entire ICD-11 code vs a single segment/component of the overall composite value. We like “code” to represent the entire value and “segment” to represent a single component of the whole, but would welcome any consistently applied terminology that provided clarity between the two types of entities.

ICD-11 Structural Issues

We realize these are likely not under the control of NCVHS, HHS, or anyone likely to see this comment, but our Data Governance Collaborative was struck by several of the choices made in the design and creation of ICD-11 codes.

Two issues stood out as extremely problematic to us:

1. Supporting individual code segments of different lengths. We understand that ICD-11 is built on composite codes with multiple segments, but in addition to the variation in length caused by differences in the number of segments, we have discovered that the individual segments are not all the same length. This seems extremely problematic from a data storage and validation perspective.
2. Some of the descriptive language for codes may be identical in ICD-10 and ICD-11 but have different meaning and be incompatible. For example, a presentation we attended in December given by NIH under the auspices of WEDI gave an example of the ICD-10 code K56.41 Fecal impaction. The ICD-11 code with the same name is a child of constipation and requires that the patient be constipated to apply the code. Unfortunately, the ICD-10 code explicitly excludes constipation and cannot be applied to patients with constipation. Thus, while the codes have exactly the same name, they are incompatible; the ICD-10 code cannot be mapped to the ICD-11 code with the same name.

Response to Specific Questions – RFI #1

This section will list specific questions asked about ICD-11 in the first NCVHS ICD-11 RFI and our responses to them.

2. What information or research will your organization need in order to inform assessments of cost, benefits, implementation approaches, communications, and outreach regarding the transition to ICD–11?

Our Data Governance Collaborative discussion resulted in quite a few areas where we feel additional research or analysis would be helpful including:

- What are the most commonly used codes in ICD-10 and what do they look like in ICD-11?
- What codes are unlikely to be used much or at all?

- Of the ~10% of codes that NIH has identified as not being compatible between ICD-10 and ICD-11, how many are commonly used?
- What percentage of organizations instituted ICD-10 codes iteratively, starting with codes deemed equivalent to what they used in ICD-9 but expanding use over time to encompass additional or more specific codes? Is this likely to be similar for the move from ICD-10 to ICD-11?
- Was the adoption of ICD-10 codes more difficult for certain types of care, specialties, settings, environments, etc. and is this likely to be similar in the adoption of ICD-11?

4. What unique U.S. coding or terminology considerations are essential? For example, coding or terminology related to community health, social determinants of health, essential human needs, sexual orientation, gender identity and expression, obesity, external cause of injury, and information about mental, behavioral, or neurodevelopmental disorders including alignment with the Diagnostic And Statistical Manual of Mental Disorders, Fifth Edition (DSM–5)?

We believe all of these areas are important. We are not familiar with what is and is not supportable via ICD-11 in the listed areas or similar types of health concerns. If supportable, some additional areas that are similar to some of those listed that might be important to capture include:

- Disability status
- Need for disability accommodations
- Diet and nutritional concerns
- Telehealth and remote monitoring information

6. The World Health Organization (WHO) recommends establishing a national center for ICD–11 implementation. What entity should be responsible for coordinating overall national implementation of ICD–11 for morbidity coding, and how should the implementation be managed?

7. ICD–11 uses an open process in which WHO encourages requests for updates and changes, thus eliminating the main drivers of national clinical modifications. What entity should be responsible for coordinating U.S. requests for updates or changes to ICD–11? How should this process be managed?

We believe the Office of the National Coordinator for Health IT (ONC), in coordination with other agencies within HHS as needed, is the right home for this oversight. Extensive feedback from industry and the public at large will also be essential, including public meetings and comment periods and explicit consultation and coordination with different types of providers, payers, vendors, and other relevant parties.

ONC is already responsible for other industry data standards such as USCDI and USCDI+. Further, there is already a process for collaborative standards definition with the USCDI+ framework. The existing ONDEC framework could be used to request updates for evaluation by ONC. If deemed appropriate, ONC could then submit these requests to WHO or their delegate for universal adoption.

A US linearization could be handled the same way, with annual or semi-annual updates released on a regular, predicable schedule using existing commenting and feedback processes.

ONC is also well positioned to ensure that new versions of the US linearization do not coincide with other major regulatory requirements such as deadlines for interoperability rules published by ONC or CMS.

8. What resources, tools, or support will your organization need for implementation?

It would be very nice to have a standard national mapping for ICD-10 to ICD-11. We understand that approximately 10% of ICD-10 codes cannot be directly mapped to ICD-11 so understanding which codes fall into this category and how to handle them in a standard way would also be extremely helpful.

11. What are your organization's requirements for ICD–11 mapping to other coding systems and terminologies, including value sets?

In order to support FHIR and common FHIR use cases, it is absolutely essential to support mapping between ICD-11 and other code sets in a bi-directional, idempotent way if at all possible. The most useful mapping would definitely be between SNOMED and ICD-11, but mappings between ICD-11 and as many other code sets with compatible codes should be developed and made available for industry use.

Response to Specific Questions – RFI #2

This section will list specific questions asked about ICD-11 in the second NCVHS ICD-11 RFI and our responses to them.

1. Related to ICD–11 content and addressing U.S.-specific needs, which enhancements in classification content would be most useful?

a. Coding to assess and address population health equity, social, behavioral, and community health

b. Coding to measure health care quality and patient safety

c. Coding for rare diseases

d. Content on other topics?

We believe that a, b, and c would all be extremely useful. We do not have a good enough sense of what is possible with ICD-11 to comment beyond that.

2. What is the potential to reduce burdens and improve quality/accuracy through the greater automation offered by the ICD–11 online classification systems?

a. How might automation reduce burdens of clinical documentation and coding for reimbursement, risk adjustment, clinical registry, and public health reporting?

b. What might be the role of artificial intelligence for your organization?

c. What might be the role of standardized cross-maps to other coding systems?

d. What other potential features could promote burden reduction?

It is unclear to us that there is a useful role for automation or AI related to the application of or upgrade to ICD-11. The quality of the underlying clinical documentation is extremely variable so using AI to analyze or process it is unlikely to be very successful.

However, as noted in comments above, it is important to provide useful, industry standard cross-maps between ICD-11 and other code systems, especially SNOMED.

We note that the application of ICD-11 codes and related processes are every bit as much human processes as tech processes. Education, workflow consistency and ease of use, training, and being aware of

organizational culture will likely yield more positive results in terms of burden reduction than trying to automate everything, at least initially.

3. What standards, systems, workforce, and processes must change to accommodate ICD–11?

a. How would your organization assess the cost and impact of these changes?

b. How might technical changes such as clustered (post-coordinated) coding be implemented in your environment?

c. What other changes are related?

As noted in the previous comment, we believe that the human factor is a major component of this process. One of the key factors to be careful about here is the implementation timeframe. If the timeframe for implementation is too far out people will ignore it because it's not imminent, but at the same time it's clear it will take a long time to implement ICD-11. This will be a challenging area to get right, but it's important. People will never believe they have enough time whatever choices are made here, so we believe it's better to err on the side of a bit faster – but within the constraints of scheduling around other regulatory requirement deadlines. If needed, there's always an option to use an enforcement delay to extend the implementation period.

We also note that clinicians usually don't code using codes, they pick terminology. As long as the terminology doesn't change significantly then clinicians likely won't experience a huge change in workflows. Overall, it's unclear how many folks at a provider office or other care setting interact directly with the codes rather than the related terminology. Updating the internal dictionary/mapping between codes and terminology is likely the largest lift at provider organizations.

4. What are the most important considerations and requirements for a U.S. governing body for ICD–11?

a. Developing and managing implementation plans and programs for ICD–11 in the U.S.

b. Developing regulations or guidance for ICD–11 applicable to your organization.

c. Ongoing management and maintenance of U.S. ICD–11 and its use.

d. Other requirements not named above?

We believe that everyone has a role to play in the adoption of ICD-11. As noted under the RFI #1 responses above, we believe ONC is the right organization to oversee ICD-11 in the US, but with coordination with CMS and other agencies within HHS as well as the industry and public at large. We were more focused on the definition and rules for maintenance and usage as well as related guidance in our thinking and did not consider all of the activities listed above (such as developing implementation plans which we see more as a local effort likely to be very different across different organizations) but some components of an overall program could be farmed out or sectioned off elsewhere with some oversight from ONC to maintain a single seat of authority if activities not in their direct wheelhouse are considered important.

Having a public-private partnership of some sort would be helpful, with some form of public meetings that go beyond invitation-only listening sessions seem warranted. It's also important to involve different types of organizations and interest areas (payers, providers, vendors, data experts, revenue vs clinical, etc.).