National Committee on Vital and Health Statistics
Advising the HHS Secretary on National Health Information Policy

ICD-11 Expert Roundtable Meeting Summary of Expert Panel Discussions: Research Topic

August 3, 2023

Questions:

a)   Considering this morning's discussion, what are the most important research questions remaining—what is missing and what is needed?

b)   What is needed to accomplish a national research agenda in a timely manner?

Group A

Facilitator: Cathy Donald

- Olivier Bodenreider
- Susan H. Fenton
- Jeffrey Linzer
- Tammy Love
- Christopher Tompkins

What are the most important research questions remaining? What is missing and what is needed?

- NLM Study – data expansion is needed
- AI capabilities – exploration of what the possibilities are but being mindful of those stakeholders who don't have access to these capabilities (Rural)
- Consider de-coupling definitions from MMS
- Need convincing cases of how to do this – what does this look like based on analytics
- Need for understanding of what has been used with ICD-10 to help inform target and intent for ICD-11
- Need research on medical education/medical school education
- Funding to pay for research by payment systems, hospitals, etc.

What is needed to accomplish a national research agenda in a timely manner?

- RFI – longer time frame and ensure coverage and input from all stakeholders how use I-10.
- Dedicated funding and resources

Group B

Facilitator: Michael Hodgkins

- Robert Anderson
- Jim Case
- Bruce Cuthbert
- James Cimino
- Renee L Johnson
- Patrick Romano

What are the most important research questions remaining? What is missing and what is needed?

- We need research into what tools are needed for implementation
  - User driven/interface
  - Functioning in the background

- Governance process/updates/maintenance process
  - WHO vs. HHS(US based oversight)
  - Perhaps through use of a pilot study

- Should US consider using SNOMED
  - Can US use a crosswalk type product to produce ICD11 data?

What are the most important research questions remaining? What is missing and what is needed?

- Credible evidence of value over ICD-10-CM
  - Various use cases presented
  - Ability to address health equity/population health/downstream application
- Research into how systems will be able handle post coordination when pre-coordinated codes are required to drive an event (either billing or patient care)?

What is needed to accomplish a national research agenda in a timely manner?

- Identify who benefits and how?
- Cost and who's paying
  - How can we make that easier for small entities?
- Coordination
  - At the federal level
  - Public/Private
- Communication
  - Pushing communication
    - What is it / benefit
    - Research agenda
  - Transition time frames
- Anticipated voluntary acceptance is unlikely/legislation needed?

Group C

Facilitator: Valerie Watzlaf

- Sue Bowman
- Carmela Couderc
- Jamie Ferguson
- Leslie Prellwitz
- Geoff Reed

What are the most important research questions remaining? What is missing and what is needed?

- What is the set of codes (stem, extension, foundation) that would be best suited for use in the US?
    - What is the frequency distribution of ICD-10-CM use over time?
    - What coverage is required for rare diseases, or for certain populations?
    - Need Pilot
- Will financial incentives make a difference. Is there a combination of financial incentives and documentation standards that would make implementation in clinical settings feasible?
    - Small practices
    - Evaluate how to mitigate costs (e.g., publication of standard, mandated mappings – what will CMS accept)
    - Training and education
- How would ICD-11 be used with the clinical documentation standards (SNOMED CT, LOINC, RxNorm)?

What is needed to accomplish a national research agenda in a timely manner?

- Funding, and directing the funding to the right places

- Authoritative coordination
  - ICD-11 will be used for more use cases than 10-CM

Group D

Facilitator: Vickie Mays

- Tammy Feenstra-Banks
- Kin-Wah Fung
- Denise Love
- Mary Stanfill
- James Tcheng

What are the most important research questions remaining? What is missing and what is needed?

- Extend Dr. Fung's research: end-to-end (EHR to codes)
- Expand scope, focus
- Data sources evaluated: example, APCD
- Start from scratch---accuracy/representative (take medical record---dual code---is it accurate, representative, better in ICD11)
- Use cases to analyze distortions in ICD10---pregnancy dx for cardiac cath for paid for pregnancy test before the cath
- Strongly encourage CMS to identify priority research according to its strategic roadmap and verify

What is needed to accomplish a national research agenda in a timely manner?

- Central coordinating entity/authority to design the entire roll out program
    - Broad representation
    - Evolving process
    - High-level model, educational/messaging component for each segment, playbook for each with roles, responsibilities,
    - Statutory authority (EHR/HIT certification)

- Research/secondary research capable (need use cases/users segments for priority populations/research, can we push detailed coded data as a benefit for research

- Private collaboration, multi-source funding

- Federal agency funded pilot maintenance process (capacity/cadence)

What is needed to accomplish a national research agenda in a timely manner?

- Mandated/uniform standard cross walk (the single standard cross walk)

- Automated coding within the workflow (e.g. EHR or other system)---demonstration, does it work, what will it take?

- Impact of I-11 on other code sets (value, cost)
  - Can we do away with SNOMED eventually? Distortion in conversion? Code direct from med record.
  - Or can they co-exist? Seamless integration/
  - Reimbursement is based on coding
  - Specialty societies ignore----fragmentation/different universes

Group E

Facilitator: Linda Kloss

- Preeta Chidambaran
- Afton Dunsmoor
- Rebekah Fiehn
- Rod Hill
- Christopher Macintosh
- Pam Owens
- Grace Singson
- Deb Strickland
- Jeffrey Swanson

What are the most important research questions remaining? What is missing and what is needed?

- Expand the broad to narrow analysis, take deep dive into other slices
  - Not focus on only mapping from ICD-10 to ICD-11 but where are the gaps (probing ICD-10 weaknesses)
  - Impact on specialty professions, independent providers
  - How will this reduce burden on providers?
- Implementation of a post-coordinated system is not simple, more details on the technology and how to achieve
- Establishing clear rules for extensions, expanding/improving the web browser
- When to start education generally, would this be same/different based on end-user purposes?
  - Need pilot studies including dual ICD-10 and ICD-11 studies
- How do we update/modernize the governance of ICD-11, how do we better understand the coordination of maintenance activities?
- Phased vs All-at-once approach for the change, what information can be gathered about impact?
- Develop technology arm of implementation. What do we need? What approach will be most equitable?
  - Tying implementation to Certification creates two systems

What is needed to accomplish a national research agenda in a timely manner?

- Make a priority and ensure it is funded.

- What entity(ies) is responsible for coordination?
  - Possibly known problem that needs to be reevaluated?
  - Ensure all parties are participating (certified vs non-certified technology and users)

- End-to-End Roadmap is needed

Group F

Facilitator: Wu Xu

- Brian Castrucci
- Eric Gardner Davis
- Charles Hawley
- Andrea Hazely
- Shannon McConnell-Lamptey
- Stella Onuhoa-Obilor
- Harold Pincus
- Amy Sitapati
- Andrew Wiesenthal

What are the most important research questions remaining? What is missing and what is needed?

- What are the most important questions?
  - Which questions can be answered retrospectively using static data? What type of data is needed?
  - Which need to be pilots with live data using pseudo-technologies-and-workflows to test the process?
- How much funding is needed to ensure any assessment of the effect of implementation represents all stakeholders?
- What education resources are needed for facility coders? What materials are needed to support other users?
- How do we know that ICD-11 can close the gaps in understanding social needs (e.g., transportation and food services), especially considering these are not currently part of claims billing and reimbursement? What is the effect this will have on social services?

What are the most important research questions remaining? What is missing and what is needed?

- How will community health clinics coordinate with EHRs?

- Alignment across federal agencies with universal data system (UDS) and guidance from ONC, particularly relevant to small and rural systems

- Recommend careful and inclusive development of use cases that must be considered; map the use cases to analyses that can be completed with
  1) retrospective analyses with existent data sets and define optimal data set for use (i.e. care for children/OB - Medicaid);
  2) prospective 'mock' evaluation

What is needed to accomplish a national research agenda in a timely manner?

- Adequate and significant funding ($1m-$50m research awards) is critical to ensuring equity and representation in our assessments.

- RFP for multidisciplinary research proposal that includes multiple key stakeholders that are adequately funded for the retrospective & real-system; identifying potential funder (e.g., foundations)

- RFP for development of education and training that has key stakeholders (rural, dental, vision, large health system, ++)

- Identifying pilot participants and target dates for using real-time encounters for testing.

- We will need a shared knowledge base with data and information.

Group G

Facilitator: Mady Hu
- Debbie Adair
- Rhonda Butler
- Rich Landen
- Krista Mastel
- Mike Newman
- Angelo Pardo
- Adele Towers
- Samson Tu

What are the most important research questions remaining? What is missing and what is needed?

- Remaining issues: Post coordination – need to understand to what extent is pre-coordination necessary for use cases – may be possible by evaluating different use cases

- Pre-coordinated terms as a standardized terminology set – same clinical meanings – can they be utilized, rolled up into the Foundation – not completely clear. Information exchange is critical. Modification process is unknown at this time for U.S. needs – will it be sufficient?

- Other countries experience
  - Payment/reimbursement

- EHR developers/vendors need to become engaged sooner rather than later – key components – other developers – revenue cycle - Artificial Intelligence (AI) – automated coding is vital. Manual process is too complex

- SNOMED CT – argument not to have CM – leverage WHO version

What is needed to accomplish a national research agenda in a timely manner?

- Need for centralized committee/center/workgroup – ineffective as of now – representation by IHS – lack of resources … need organization. Need dedicated, devoted center to support the work needing to be accomplished. Sole purpose to meet goal.

- Inventory – who are the participants, key stakeholders to involve? Governance and oversight of efforts?

- Who will be performing the tasks? How will it be accomplished? Governance issues related to the goal of implementation.   More information as a result of the RFI – will prioritization occur? Who is responsible for coordinating, organizing and gathering? What is the timeline? We need a roadmap….

- Research questions will inform governance. Complete mapping is necessity – government agency must complete. Post coordination must be performed. Case studies, funded projects, vendors and stakeholders. ICD-10 to ICD-11 mapping – compatibility back to ICD-9. Is the intent to have a direct mapping similar to GEMs? Approximate mappings.. SNOMED – same issues. Follow trends – population health multiple generations – consistency in concepts. Generational trends.

What is needed to accomplish a national research agenda in a timely manner?

- Timing, communication, - limited resources – workforce/staffing – financial burden – who will bear that?   Critical care providers… Payment, research, drivers – clinical care questionable… - not the experience realized…   Who will benefit???

- Digital classification ICD-11 – created coding tools and browsers for use – U.S. needs a system to leverage common software to facilitate for stakeholders – organize for public domain. Freely available so it can be integrated using FHIR Critical decision support tool apps that do no require other access