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: Continuity & Sustainability Topic

August 3, 2023

Questions:

c) Who and what organizations need to be involved moving forward? Are there specific agencies and organizations whose involvement is needed for specific studies?

d) How to coordinate and sustain this community to obtain needed information to support NCVHS' recommendations to HHS?

Group A

Facilitator: Cathy Donald

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

Who is best positioned to lead the overall project or specific parts of the project? Are there organizations and agencies that MUST be included for longitudinal success of ICD-11 implementation?

- Public/Private (who to be determined?) – to **LEAD** the overall project. Similar to Cooperating Parties to LEAD overall project. Specific parts of the project may need to be determined as applicable.
- CDC/NCHS, CMS, VA, AHRQ, NIH, IHS
- AHA, AHIMA, HIT and EHR vendors, Clinical Data Scientist organizations
- Principal primary care societies including AIP, AAP, AAFP, ACOG, ACS and ACEP as well as the AMA
- Studies specific to the organizations involved – funding for the studies, what are the needs and interests to be gained by ICD-11 and the impact to each organization
- Longitudinal success – will need to involve the same groups but consideration of new groups as the process of implementation moves forward
- Governance group establishment while a blue-print is being drafted

What is needed in the United States that is fundamentally different from other countries? Are there essential next steps in priority order?

- CM Clinical modification – certain things that the MMS doesn't have.
  - Social determinants of health for example

- Diagnosis definition could put clinicians at risk. Need to continue current diagnosis guideline using concept of "highest level of clinical certainty" being the determinant of diagnosis

Group B

Facilitator: Michael Hodgkins

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

Who and what organizations need to be involved moving forward? Who is best positioned to lead the overall project or specific parts of the project?

- National Library of Medicine
  - strength of NIH as neutral party
  - agenda neutral
  - experiences with a variety of terminologies
- Potential attributes of a new entity to be created
- Or perhaps a neutral third party
  - A group that focuses on where the data come from
  - Concern regarding stakeholder agendas

Are there organizations and agencies that MUST be included for the longitudinal success of ICD-11 implementation?

- Every federal agency that touches healthcare
- WHO
- Umbrella organizations that organize stakeholders eg. AMIA, AHIMA, EHRA, AHP
  - Health Plans
  - Academic Centers
  - Health Information Management Systems
  - EHRs
- Vendors that will develop and sell products related to the change
- Artificial Intelligence partners/Big tech companies
- State governments

How to coordinate and sustain this community to obtain needed information to support NCVHS' recommendations to HHS?

- Emphasize the need for a more extensive RFI to obtain input from the public and stakeholders
- Question: Do we need to have an organization designated with the authority and financing to make decisions – and what it creates gets implemented?
- Development of an engagement plan for soliciting partners

Group C

Facilitator: Valerie Watzlaf

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

What is needed for continuity and sustainability over time?

- Continued engagement from organizations and individuals participating in the Workgroup
- Workgroup report to include a schedule of ongoing meetings/work sessions
- On-line presence – enhance existing Workgroup website
  - Explore community collaboration tools
- Obtain funding for sustained resource allocation
- Expand participating stakeholders

Priorities

- ICD-11 implementation scope definition, e.g., use case scenarios, including and beyond HIPAA
  - Are there clinical documentation use cases?
    - behavioral/mental health domain?
    - social and community health?
- How will ICD-11 impact quality measures?
- Communicate patient safety benefits

Who and what organizations need to be involved moving forward? Are there specific agencies and organizations whose involvement is needed for specific studies?

- Maintenance and management: **WHO**
- Nations that have implemented ICD-11 who have clinical modifications
- Mapping studies: National Library of Medicine (**NLM**), code system stewards/standards organizations, (American Medical Association **(AMA), Regenstrief, SNOMED International**)
- Quality and Safety: Agency for Healthcare Research and Quality (**AHRQ**) and Joint Commission
- Longitudinal data: America's Health Insurance Plans (**AHIP**), multi-state all payer claims database (APCD)
- Financial incentives/penalties: Centers for Medicare and Medicaid Services (**CMS**), Office of the National Coordinator for Health IT (**ONC**)
- What does it take to facilitate the change? Input from specialty societies? What does it take to make this work in practices: **AMA**
- What components of ICD-10-CM are used, and what is not used; how does this inform ICD-11: AHIP
- Training and education: **AHIMA**

How to coordinate and sustain this community to obtain needed information to support NCVHS' recommendations to HHS?

- **Health and Human Services**
  - ONC – Office of the National Coordinator for Health IT
  - CMS – Centers for Medicare and Medicaid Services
  - CDC – Centers for Disease Control and Prevention
  - AHRQ – Agency for Healthcare Research and Quality

Group D

Facilitator: Vickie Mays

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

We've identified research questions, stakeholder, benefits, and other issues. What should be done to maintain the momentum?

- **Best positioned:**
  - Entity needs to build relationships, coordinate, develop the program, managing funding opportunities
  - Have to decide what agency: National Academies (NASEM) as an ignitor
  - Appoint a ICD-11 Czar or Czarina as point person to make initial operational decisions
  - Overall lead: Governmental and non-governmental process (once there is start-up legislation/goals/funding
- **Organizations:**
  - NCHS/CDC, ONC, NIH/NLM, OBRHI/CMS, HRSA, AHRQ
  - AMA, AHA, AHIMA, NAHDO, AHIP, ADA, HIMSS, IFHIMA, AAPC, professional societies, International (WHO)
- **US Difference:**
  - Reimbursement tools (DRGs, VBC, capitation), that accounts for diversity size, fragmented health care system

Essential Next Steps

- Appoint a Leader
- Enabling legislation/regulation
- Funding
- Identify responsible entity
- Develop structure:
  - Steering committee
  - Advisory committee

Group E

Facilitator: Linda Kloss

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

We've identified research questions, stakeholders, benefits and other issues. What should be done to maintain the momentum?

- Who is best positioned to lead the overall project or specific parts of the project?
  - HHS to fund initial coordination
  - Initial effort of coordination – this committee needs to be STAFFED with a coordinator and expanded with task forces
  - Design a governance mechanism going forward
  - Clinical efficacy continuation of the complete the slices - identifying gaps
  - Implementation road map
  - Technology arm – challenges, eventual tool-kit
  - ++ - all questions from round-table to feed task force development

Long term coordination – political and funding hurdles before we get here (TF work)

- New entity – public/private for terminology classifications in healthcare

What should be done to maintain the momentum?

Organizations and agencies that MUST be included for the longitudinal success of ICD-11 implementation:

- Providers, payers, policy makers, technology vendors, public health
- Coordination of terminologies and classifications
  - HHS, NLM, CMS, AMA, ADA, LOINC, SNOMED

What is needed in the United States that is fundamentally different from other countries?

- Analysis of implementation so far working with WHO

What should be done to maintain the momentum?

- Are there essential next steps in priority order?
  - Funded NCVHS coordinator staffing the work of an expanded committee
  - Design a governance mechanism going forward
  - Clinical efficacy continuation of the complete the slices - identifying gaps *
  - Implementation road map *
  - Technology arm – identify challenges then create tool-kit *
  - Pilot studies targeting all users *
  - Education in phases and audience based
  - Awareness before training

*Could be part of an iterative process

Group F

Facilitator: Wu Xu

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

Who is best positioned to lead the overall project or specific parts of the project? Are there organizations and agencies that MUST be included for longitudinal success of ICD-11 implementation?

- **Key leading agencies/org. for national:** (potential candidates) CMS, CDC (i.e. public health), NIH (i.e. Fogarty Center, NLM, research, +), AHRQ (i.e. USPTF, quality, outcomes), FDA (i.e. drug, AI,), HRSA (i.e. FQHC), VA/Active military, IHI (i.e. international), SSA (i.e. ability), NCQA, AMA, Specialty Societies (i.e. mental health, Am. College of Card., +), AHA (American Hospital Assoc.), AMIA, AHIMA, National Association of Healthcare Quality (NAHQ), Software developers & terminology maintainers (i.e. 3M), EMR Vendors (i.e. Epic, Cerner, +), Patient groups, Payers (i.e. Health plans,), Public Health Associations (Am. Public Health, Am. AcademyHealth), Health Research Organizations, AAMC, Disability Rights Org., Foundations (i.e. fund initial priority studies, speed), Congressional allocation of $ (?)

- **Who is best poised**? (not one – this requires a community multi-agency partnership) Regulation will require a governmental agency. Considerations might include: CDC, CMS, ONC. Reflect on prior ICD-10 gaps/lessons learned and how to mitigate and be more inclusive as well. Review existing source documents to inform. Private-public partnership funded by foundation (i.e. to promote speed, inclusivity)

How to coordinate and sustain this community to obtain needed information to support NCVHS' recommendations to HHS? What is needed to support the community?

- **How:** Define governance, new roles, and funding: Responsibilities will require coordination with WHO (who would be best suited to serve in that coordination?, NCHS now – what about future?)
- **Inclusive Participation:** public, private, all partners in ICD10 maintenance 'participation' (i.e. buy-in, expertise), State and local entities will need incorporated
- **Break viewpoint into** (1) Implementation and (2) Longitudinal Maintenance. Continuous ongoing need (i.e. could be opportunity to build longitudinal network of key individuals instead of 'implementation')
- **What:** Define clear staged goals and processes (i.e. phases, timelines, agencies, etc.)
- **Disseminate:** Transparency and Communication

Group G

Facilitator: Mady Hu

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

For continuity & sustainability, what should be done to maintain the momentum?

- **Who is best positioned to lead the overall project or specific parts of the project?**
  - Public vs. Private? Separate issue from Rulemaking – needs to be a partnership. Federal and non-Federal components – NLM and/or NCHS – consortium of agencies under a Lead. Health information networks, tribal/territorial aspects.
- **Are there organizations and agencies that MUST be included for the longitudinal success of ICD-11 implementation?**
  - How do we identify them? Maintenance and updates of code set – will it be restructured? What is future role for current Cooperating Parties (AHA, AHIMA, CDC, CMS) for ICD-10? Updates and education? Communication strategy/messaging needs to be performed in advance – provide full picture/timeline/financial aspects. Full assessment needs to be communicated. Lobbyists – health insurance trade associations… communicate benefits – try and keep them neutral. Stay ahead of it…. Finances need to be considered and factored in. Stress values and opportunities that will come with transition to ICD-11. Engage slowly and cautiously … slow build up .. Use lobbying levers. Ex: National Association of Rural Health Clinics.
  - HRSA, AHRQ, NLM, NCHS, AHIP, BCBS
  - Providers/Professional Organizations – MGMA, HBMA, AMA, IHS, VA, ADA, HIMSS, AMIA, etc.
  - X12 and other Standard setting organizations

For continuity & sustainability, what should be done to maintain the momentum?

- **What is needed in the United States that is fundamentally different from other countries?**
  - What is not different? Mortality and Research
  - How ICD is embedded in our payment system. CM needs? Do we need modifications or not?
  - Governance in US not international agencies
  - Coordination and outreach, education due to lack of single payer system – we have a complex, hybrid system with several stakeholders – no centralized authority. Other countries' experience will not match the U.S.

- **Are there essential next steps in priority order?**
  - Find entity to fund and coordinate needed research
    - Can we increase the visibility of ICD-11? (Ex: will Google or Microsoft express interest??)
  - White House to designate lead federal agency
  - Determine if CM needed or not – Need the Mapping to be completed
  - Timeline/Roadmap