

National Committee on Vital and Health Statistics
Workgroup on Timely and Strategic Action to Inform ICD-11 Policy
aka “ICD-11 Workgroup”

ICD-11 Workgroup Charge

This document defines the activities, membership, and administrative requirements associated with the establishment of the National Committee on Vital and Health Statistics (NCVHS) Workgroup on Timely and Strategic Action to Inform ICD-11 Policy, (“ICD-11 Workgroup”). The purpose of the Workgroup is to gather information from a broad range of sources to bring to the full Committee in its effort to develop advice and recommendations to HHS regarding adoption of ICD-11 as a Health Insurance Portability and Accountability Act (HIPAA) code set.

Background: The World Health Organization (WHO) initially released ICD-11 in 2018, a scientifically updated, state of the art technology adopted by WHO to become the de facto global standard for health data disease classification. NCVHS noted that much is unknown about the implications for the United States transitioning to this version, and the Committee held an expert roundtable in 2019 to begin an assessment. In 2019 and again in 2021, NCVHS sent recommendations to the Secretary that proposed a set of research questions, the answers to which would inform timely and rational development of United States (U.S.) policy for ICD-11 implementation.^{1,2}

NCVHS finds that immediate action is needed if the U.S. is to avoid repeating for ICD-11, the many costs and resource burdens that characterized its late implementation of ICD-10. One important goal in the adoption of ICD-11 is to avoid, if possible, a full U.S.-specific clinical modification as occurred for ICD-10. In its role as an advisory committee to the Secretary, NCVHS intends for this project to support HHS in leading the U.S. in preparation for policy and implementation decisions regarding ICD-11.

Description Of Activities

The ICD-11 Workgroup’s information-gathering will include conducting a review of research studies and findings (peer-reviewed and in the gray literature from the U.S. and internationally) and gathering input from subject matter experts to inform and, when possible, answer the Committee’s questions and related issues regarding ICD-11, including but not limited to:

1. Studying the issues (costs, benefits, challenges) involved in a transition to ICD-11 in the U.S. This could include conducting an environmental scan on the ICD-11 research, outreach, and communications that has already occurred, or been initiated, specific to ICD-11.
2. Engaging key stakeholder participation in meaningful national dialogue, such as convening an expert roundtable meeting and launching a public/private collaborative to facilitate research of the essential questions, e.g., impact of structural differences of ICD-11 from ICD-10 on data standards used for reporting, recording, billing, quality measurement, and interoperability (as none can handle post-coordinated codes from ICD-10); identify gaps in research activities and promote conduct of research to fill identified gaps.

¹ NCVHS ICD-11 Expert Roundtable Meeting August 6-7, 2019: <https://ncvhs.hhs.gov/meetings/subcommittee-on-standards-icd-11-evaluation-expert-roundtable-meeting/>

² NCVHS Recommendations for Immediate Action on ICD-11 (Sept 10 2021): <https://ncvhs.hhs.gov/wp-content/uploads/2021/09/NCVHS-ICD-11-recommendations-for-HHS-Sept-10-2021-Final-508.pdf>

3. Analyzing input from convenings and research activities; highlight conclusions from the research; and develop findings and outcomes for consideration by the full Committee.
4. Organizing the findings from these activities to inform development of advice and recommendations from NCVHS to the HHS Secretary that may result in formation of future U.S. policy facilitating the transition to and implementation of ICD-11.
5. Reviewing previous Committee recommendations to HHS regarding initial outreach and communications activities and providing the full Committee with any new information that would be used to support development of new or revised recommendations.

Areas of focus may include:

- a) Assessing available evidence and make initial observations regarding whether or what type of clinical modification to ICD-11 may be necessary to achieve adequate content coverage with ICD-11 codes, or whether more research on this is needed, or whether WHO ICD-11 is adequate for U.S. purposes.
- b) Identifying anticipated benefits, and costs, of moving to ICD-11 for morbidity classification including barriers to implementation, e.g., readiness as a reimbursement tool, effect on Diagnosis-related Groups (DRGs) and grouper software, preparation of older databases to integrate ICD-11 with prior ICD-9 and ICD-10 data, etc.
- c) Evaluating the impact of not moving to ICD-11 for morbidity coding use cases.
- d) Appraising the ability of ICD-11 for public health applications, e.g., accurate data that can be used to track and understand worldwide pandemic variants, design effective public health policies, epidemiological research, and the utmost in quality and patient safety in the prevention and treatment of health issues.
- e) Assessing whether ICD-11 will reduce provider burden, increase interoperability of electronic health information, or promote health informatics.

Workgroup Membership

The Workgroup will be established under the NCVHS and will include at least two Special Government Employees (SGEs) who are members of the Committee. One of the SGEs will serve as Chair of the Workgroup. The Workgroup will also include a Designated Federal Officer (DFO), who is a full-time or permanent part-time CDC employee.

The Workgroup will be comprised of a minimum of 8 and a maximum of 15 members and will strive to include those with expertise in health informatics and information management, population health, research methodologies related to clinical classification systems and terminologies, reimbursement (DRGs, etc.), clinical medicine, electronic health record systems, data quality, patient safety, equity, and/or tribal health.

Due to the complexity and variability of information to be gathered, additional non-governmental external subject matter experts (SMEs) may be invited to provide input during Workgroup meetings on an ad hoc basis as needed to provide topical expertise as determined appropriate by the Workgroup

Chair and CDC DFO. Such additional external SMEs will not be members of the Workgroup; their role will be to provide information as requested by Workgroup members.

Meetings, Administration, and Timelines

1. Administrative Oversight: The Workgroup DFO will work with the Workgroup Chair to arrange meetings, document meeting proceedings, and reporting to the full NCVHS membership on Workgroup findings.
2. Meeting structure: Meetings may only be convened with two or more SGE Workgroup members attending. Meetings are anticipated to be set up as video conferences.
3. Meeting frequency: The Workgroup will meet as often as needed to address specific issues and to carry out development of Workgroup products. It is anticipated that there will be a minimum of six meetings.
4. Timeline: The Workgroup will hold its first teleconference in the 1st quarter of 2023 and anticipates a minimum of one year of information-gathering activities. The Workgroup plans to provide initial findings to the Committee by the end of 2023. It is anticipated that the Workgroup may need to continue meeting to gather information and await results of research activities conducted by academic and private-sector organizations over an extended period. The Workgroup may be asked by the full Committee to provide additional information and answer additional questions upon the Committee's review of the initial findings.
5. Conflicts of Interests: Non-SGE Workgroup members will read the "Conflict of Interest and Confidentiality Information for Workgroup Members" guidance and will complete the "Conflict of Interest and Confidentiality Certification for Workgroup Members" (CDC Form 0.1473) to disclose interests (e.g., employment, special interests, grants, or contracts) that a reasonable person would view as conflicts or potential conflicts of interest with their Workgroup participation. If a Workgroup member indicates a potential or actual conflict of interest, the DFO will advise the member to recuse from participation in Workgroup discussions that implicate the conflict-of-interest concern. The discussions of the Workgroup may include information that is unpublished, protected, privileged, or confidential. Information of this nature must not be disseminated, distributed, or copied to persons not authorized to receive such information.
6. Subject content: Findings and opinions of the Workgroup members will be discussed at Workgroup meetings. A summary of the Workgroup's findings will be presented to the full Committee for discussion, deliberation, and decisions regarding the advice and recommendations that will go forward to HHS. The Workgroup itself will not deliberate, vote or advise the Department directly.
7. Federal Staff involvement: The Workgroup plans to seek input from the Centers for Medicare & Medicaid Services, the National Institutes of Health, CDC, Office of the Assistant Secretary for Planning and Evaluation and other HHS subject matter experts for consultation or informational presentations that contribute to the Workgroup's tasks. Participation by and contributions of federal staff must be transparent and evident, to preclude the risk or the appearance of undue influence that would compromise independence. The full Committee and Workgroup DFO will ensure that Workgroup products are appropriate and not influenced by HHS or by any special interest group.
8. Workgroup Meeting Summaries: Summary documents will be created from each Workgroup meeting. Workgroup documents provided to the full Committee for consideration and deliberation in a public meeting will become part of the Committee's official records. The Workgroup Chair will present meeting summaries and materials to NCVHS for discussion, deliberation, and consideration, and for determining recommendations to be issued by the full Committee.

Recordkeeping And Reporting

The Workgroup Chair will present meeting summaries and the final work product(s) to NCVHS for consideration and for determining recommendations back to the agency. NCVHS advice and recommendations will be included in the Committee's official meeting minutes and annual comprehensive review report.