

Classification and Statistics Advisory Committee (CSAC) ICF Annual Report 2024

14-18 October 2024

WHO-FIC

Poster Number
101

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Abstract This poster presents the purpose and main activities of the Classification and Statistics Advisory Committee (CSAC) ICF and presents a preliminary report of the work of the Committee during 2023-2024.

Introduction

The Classification and Statistics Advisory Committee (CSAC) was launched at the Mexico Network meeting in 2017. It replaced the Update and Revision Committee.

The purpose of the CSAC is to provide strategic and technical advice to WHO and the WHO-FIC Network in keeping its Family of International Classifications up to date in line with current knowledge, and relevant to the purpose for which they were designed.

The functions of the CSAC are to maintain the Family of International Classifications, in maintaining policy, and maintaining work¹.

The CSAC ICF is chaired by Masahiko Mukaino and secretariat support is provided by Paula Tonel.

Methods & Materials

CSAC work is conducted through the WHO-FIC Maintenance platforms. These are workflow engines designed to facilitate communication within expert workgroups and ensure transparency of processes².

Work and communications are also carried out via e-mail, conference calls and meetings, including during the WHO-FIC Network annual meeting.

Activities of the CSAC are carried out in accordance with the WHO-FIC Strategic Work Plan.

Activities 2023

Work on ICF version in the new platform

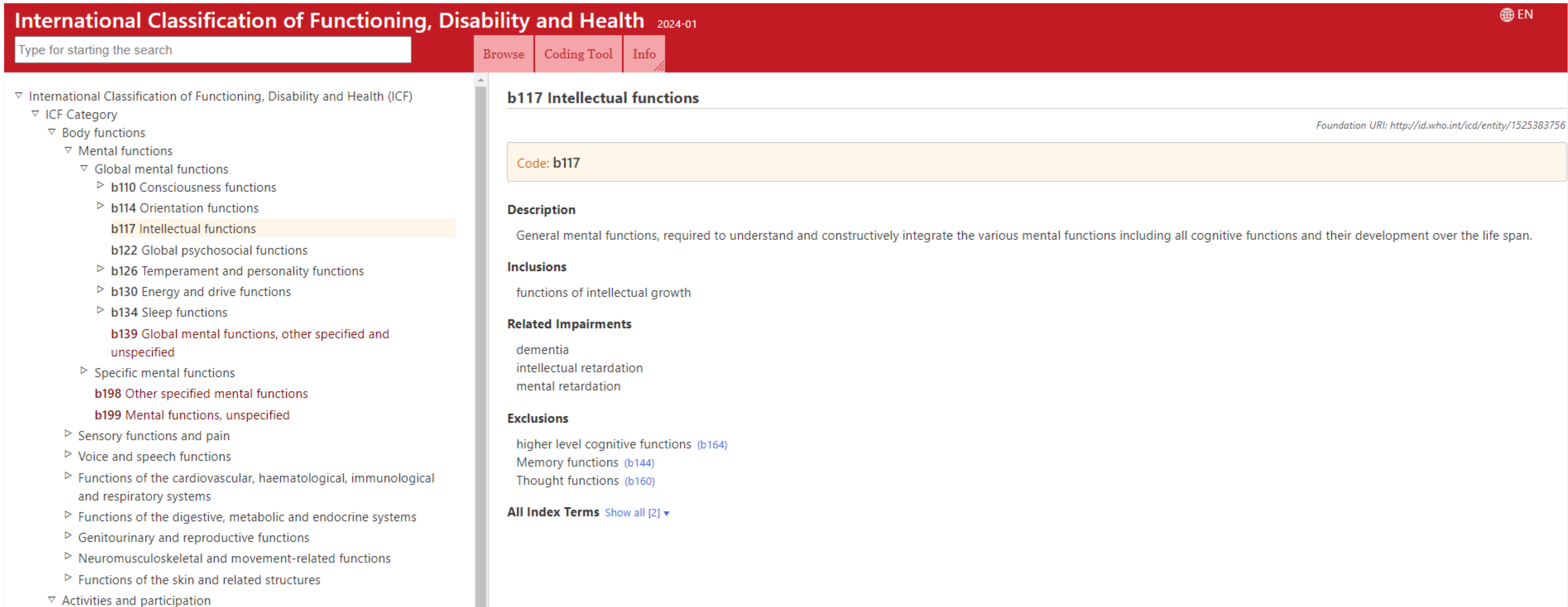
In late 2023, significant progress was made on the ICF version in the new platform. A key issue was the implementation of 69 update proposals approved by CSAC ICF between 2018 and 2020. Challenges arose in integrating 16 pending updates with major changes, previously discussed in preparatory teleconferences by voting members. The meeting addressed these integration challenges, presenting and discussing potential solutions. After thorough deliberation, the decision was made to proceed with the pre-release version. Additionally, a postcoordination mechanism for the ICF qualifier scale was activated in both the new platform and the Coding Tool.

Activities 2024

ICF 2024 pre-release

A new ICF version (Figure 1) was made available (<https://icd.who.int/browse/2024-01/icf/en>). As previously mentioned, this version included the implementation of all 2018+ approved ICF updates. CSAC-ICF members were asked to review the ICF 2024 pre-release and provide feedback. Comments received from the members were then considered by the CSAC ICF co-chair together with WHO.

Figure 1. ICF pre-release 2024



Guideline for submission of ICF update proposals on the maintenance platform

A guideline document to help authors to submit proper proposals in the new platform was prepared by the CSAC ICF Co-chair and Secretariat together with WHO. The document was sent to CSAC ICF members for review and feedback.

Triage work for ICF update cycle 2024

Triage work on the **35** proposals present the ICF platform was conducted by the CSAC ICF co-chair and Secretariat together with WHO.

The work was conducted through teleconferences and emails. The outcomes of the triage work are summarized in Table 1.

Table 1: Outcome of triage work

Outcome	Number of proposals
Back to author	12
Rejected	3
Implemented under technical trust	10
Referred to FDRG	4
CSAC ICF voting	4
Staying in submitted	1
SPAM	1
Total	35

ICF updates 2024

4 proposals were referred to CSAC for voting in 2024.

Virtual information sessions were held with CSAC ICF voting members and proposals documents were provided.

Voting round is open and will end on 22 September.

Work with other groups or committees

CSAC ICF continued to work closely with other committees and reference groups. The CSAC ICF Co-chair participated in MSAC monthly meeting as Ex officio member. The CSAC ICF Co-chair and secretariat also participated in FDRG meetings or teleconferences.

Acknowledgements

The achievements of the Committee are made possible by the generous efforts of CSAC members and relative institutions.

References

1. Conduct of the WHO FIC Network. Annex 2: Terms of Reference of the WHO-FIC Classification and Statistics Advisory Committee (CSAC). <https://www.who.int/classifications/ConductoftheWHOFICNetworkupdated20181029.pdf?ua=1>
2. The ICF Maintenance Platform <https://icd.who.int/dev11/l-icf/en/#/>



Education and Implementation Committee Annual Report 2023-2024

14-18 October 2024

WHO-FIC

Poster Number

102

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Abstract The Education and Implementation Committee (EIC) assists and advises the World Health Organization (WHO) and the WHO-FIC Network in implementing WHO classifications. The primary functions of the Committee are to develop strategies for the implementation of the WHO-FIC with an integrated educational approach for the Reference Classifications. This poster presents a summary of EIC activities and achievements from October 2023 to October 2024.

Introduction

The EIC is a cross-cutting committee which collaborates with the WHO-FIC reference groups including the Mortality Reference Group (MRG), the Morbidity Reference Group (MbRG) and the Functioning and Disability Reference Group (FDRG). The EIC in consultation with the WHO-FIC Reference Groups facilitates improvement in the level and quality of the use of the reference classifications in the WHO member states. The EIC plays an integral role in supporting WHO in education and implementation activities for the family of international classifications as defined by the WHO-FIC Strategic Work Plan (SWP) and annual priorities. This poster presents the progress of workplan activities undertaken by the EIC members in 2024.

EIC meeting schedule

The EIC activities were progressed through:

- Quarterly virtual calls with EIC members on 15 February, 26 June, 11 September and 16 October.
- Monthly teleconference calls with Cochairs, WHO and Secretariat
- EIC member volunteers contributing to the 2024 SWP activities
- EIC closed collaboration workspace to share meeting papers, presentations and updates on SWP progress (hosted by the UK Collaborating Centre).
- ICD-11 Implementation Forum for virtual discussion, open to all WHO-FIC members and officially nominated member state representatives to network and share information and experiences about ICD-11 implementation (hosted by the UK Collaborating Centre).

SWP 1: Education

WHO ICD-11 Education Tool:

Volunteers from 6 countries and IFHIMA have been involved in the following work:

- Phase 2a - Volunteer sub-group reviewed the re-draft of Units 4-10 including alignment with latest 2024 ICD-11 release by mid-March 2024

SWP 1: Education (contd)

- Phase 2b – Volunteers completed review of Units 1,2,3,11 and also user guides by end of January 2024 The Australia Collaborating Centre provided the resources to complete the edits in the tool ready for handover to WHO and publication. Work is progressing as follows:
- Units 1, 2, 3, 10 and 'how to guides' are anticipated to be delivered before Annual Meeting 2024.
- Units 4, 5, 6, 7, 8, 9 were completed and transferred to WHO mid-July 2024
- Units 11 (TM) and 12 (Section V) are awaiting input from TMRG and WHO respectively.

WHO Academy ICD-11 course modules

The EIC have assisted WHO in the development and review of the WHO Academy ICD-11 course materials.

EIC members from Argentina, Australia, Canada, Japan, Republic of Korea, and United Kingdom gave comprehensive input on country education assessments as reported in October 2023; based on this input the WHO team have since confirmed there is no further need to expand the survey of country coding assessments. WHO will confirm any additional input from the EIC for the following modules:

- 'Basic Coding with ICD-11' - the WHO team have completed the storyboard and will now progress the production phase.
- 'Fundamentals 02: ICD-11 Coding and tooling environment', 'In-depth: Mortality Coding with ICD-11' and 'In-depth: Medical Certification'.

SWP 2: Implementation

ICD-11 Transition and Implementation Guide review:

In February 2024 WHO sought input from the EIC members to enhance the ICD-11 Implementation or Transition Guide. There are two topics that are consistently raised with WHO and of priority concern.

The associated sections in the guide are:

SWP 2: Implementation (contd)

- Section 2.4.5 Crosswalks (mapping) and comparability
 - Section 2.4.6 Dual coding studies.
- The objective of the EIC task was to update the guide by improving explanations, giving practical examples and signposting to resources. Both sections were presented and discussed on Quarterly meetings. The topics were also posted on the WHO-FIC ICD-11 Implementation Forum to broaden discussion and gather input based on country implementation plans and experience to date to enrich the content of the Guide. EIC members were asked to submit responses to a Dual Coding oriented questionnaire by end of August 2024 and use cases will be developed to expand the two topics.

WHO-FIC Implementation Forum

All WHO-FIC Committee and Reference Group members and ICD-11 country focal points were invited to join the closed workspace. In 2024 a total of 140 CRG members and focal points have joined the Forum workspace. With WHO agreement the WHO-FIC Head of Collaborating Centres were invited to nominate additional members that are working on country ICD-11 implementation to join the forum and enrich the discussions, exchange of information and experiences.

Digital Adaptation Kit (DAK) for Verbal Autopsy (VA)

EIC members were invited by WHO to review, comment and make suggestions on the document in relation to implementation of verbal autopsy in digital systems.

Acknowledgements

The authors would like to acknowledge and thank Sue Walker from the Australian Collaborating Centre for her leadership and contributions to the EIC over the past 30 years and representation of the Western Pacific Region and wish her well in retirement.



FDC ANNUAL REPORT OCT 2023-OCT 2024

14-18 October 2024

WHO-FIC

Poster Number

103

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¹FDC Co-Chairs, ²FDC Secretariate

Abstract The Family Development Committee (FDC) aims to develop and maintain the World Health Organization's Family of International Classifications (WHO-FIC) as an integrated and comprehensive suite of classifications that provide a common language for health information across the world. It also aims to ensure that the WHO-FIC reference classifications have a logical and unified structure with the complement of related classifications to fulfil any gaps in coding health information across settings. The poster will present a summary of the FDC activities from Oct. 2023 to Oct. 2024.

Introduction

The tasks of the Family Development Committee (FDC) detailed in the Strategic Work Plan (SWP) have been addressed along the year with special emphasis on items falling within some of the FDC Terms of Reference mandates to:

1. serve as a focal point for the Network for the finalization of ICHI.
2. oversee the work on content alignment and harmonization across the three classifications:
 - International Classifications of Diseases 11th Revision (ICD-11)
 - International Classification of Functioning, Disability and Health (ICF)
 - International Classification of Health Interventions (ICHI)
3. oversee the expanded mapping of WHO-FIC across UHC health indicators.
4. identify and describe joint use of the WHO-FIC reference classifications.
5. oversee review of the Family paper and criteria for related classifications/terminologies.
6. Linked ontologies/terminologies.

Methods & Materials

The activities have been developed through three modalities:

- Teleconferences among co-chairs and WHO
- Mid-year hybrid meeting held in Mexico City 11 May 2024. Joint session with Informatics and Technology Committee (ITC).
- Dedicated small working groups and meetings with these working groups
- Meetings with ITC Co-Chairs for collaborative work involving the content alignment and harmonisation.

SWP 1 Finalising of ICHI

Work has continued towards the finalization of ICHI for implementation. ICHI is stable and is already implemented in some countries.

The residuals are under review. Updates of extension codes in progress. ICHI Reference Guide needs updating such as focusing on using the Coding tool. Goal is to update ICHI browser to make it more user-friendly.

The ICHI content alignment and harmonization with the WHO-FIC Foundation has continued during 2024 such as review of the maps of ICHI anatomical targets to ICD-11 extension codes to ensure consistency across the three classifications. This work is a part of the SWP 2.

The ToR for the Health Interventions Reference Group has been approved by the Council.

SWP 2 Content Alignment and Harmonisation

This work is being done jointly with the ITC. The overall aim of this work is to align and harmonize the content in the Foundation to promote semantic consistency and interoperability. A summary of four years work is presented in two posters.

Anatomy and topography of the reference classifications.

The maps of the ICF body structure and the ICHI anatomical targets to ICD-11 extension codes for Anatomy and topography have been used to create hypothetical views of the anatomy in the Foundation. The next step is for experts to validate the hierarchy before making it part of the Foundation (separate poster).

Workflow for changes in the WHO FIC foundation.

This involved a review of current processes and a discussion of how a harmonized WHO FIC Foundation may impact the update processes to the classifications.

We give three examples of content harmonization, describing the entities involved, the methods needed, the results, their impact on the classifications, and the governance process likely required.

FDC will lead the task of structuring items in the inventory of potential overlap into topic areas. The relevant committees and reference groups will be asked to prioritize the topics, analyze them along the line outlined in this poster, and recruit experts to carry out the harmonization work as part of the WHO-FIC Network Strategic Plan (separate poster)

SWP 3 UHC Mapping

The frozen version (2023) of the maps of the health indicators to the reference classifications have been published at WHO webpage. Next step is to update the maps to actual version of the reference classifications and to develop a plan for maintaining the maps.

SWP 4 Joint Use Cases

As part of the 2022-2025 Framework for the WHO FIC Network SWP, FDC has developed several use cases of joint use of reference classifications. The template has been updated to version 2. Several new use cases have been submitted and earlier use cases have been updated (separate poster).

SWP 5 Family paper

The Family paper is under review to also include related terminologies. A review of the criteria for related classifications/terminologies is ongoing.

Next steps are to:

- review the related classifications according the criteria
- have an updated version of the Family paper for approval at the 2025 annual meeting.

Mapping ICPC-3 to ICD-11

306 entities in ICPC-3 have been mapped to ICD-11 and checked against the ICD-11 Low resources version to evaluate the coverage in ICD-11. The result showed that 80 percent of these entities in ICPC-3 have exact match to ICD-11. More details are presented in separate poster.

SWP 6 Linked ontologies/terminologies

The plans are to enrich the Foundation by linking content from ontologies/terminologies. Ongoing projects include Mondo, MedDRA, RadLex®, MeDevIS.

Acknowledgements

The FDC co-chairs and secretariate thank Robert Jakob, WHO and the FDC members and working groups for their contributions to the FDC work plan activities during the year, especially the dedicated working groups.

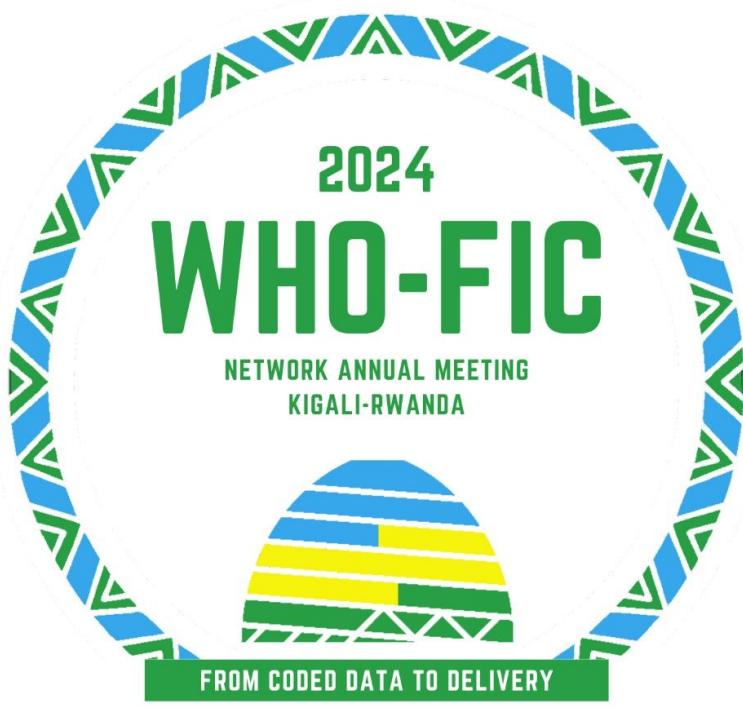
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Abstract

In 2023-2024, Informatics and Terminology Committee (ITC) worked on updates of tools and technologies that support the WHO-FIC classifications, issues related to the alignment and harmonization of WHO-FIC Foundation content, the integration of ICD-11 and the Mondo disease ontology, and on the technology that can provide semi-automated support for terminology mappings, such as mappings from ICD-10 country modifications to ICD-11.

Introduction	Issues Related to WHO-FIC Foundation Harmonization	Mondo/ICD-11 Integration
<p>The Informatics and Terminology Committee (ITC) seeks to fulfill its mission by providing a forum for WHO headquarters (HQ) developers and collaborating centre representatives to meet and to work on assignments from the WHO HQ, leveraging the expertise of both ITC members and colleagues from other committees and reference groups. The work is governed by the priorities set in the WHO-FIC Strategic Framework and Work Plan. In 2023-24, the work of the ITC focused on: 1. WHO-FIC platforms and software tools, including the Digital Open Rule Integrated cause of death Selection Tool (DORIS) and APIs; 2. Investigating issues related to WHO-FIC Foundation alignment and harmonization that is coming to a conclusion this year; 3. Mondo/ICD-11 integration; and 4. evaluation of terminology mapping and ontology alignment software.</p>	<p>In 2020, WHO incorporated ICF and ICHI into ICD Foundation based on a generalized WHO-FIC Content Model. The resulting Foundation contains numerous areas of overlap. For example, ICF Anatomy and topography extension codes, ICF Body structures, and ICHI Targets for body systems and functions all contain anatomical concepts. ITC and the Family Development Committee embarked on a project to investigate issues related to the harmonization of the Foundation content. The work was divided into seven areas:</p> <ol style="list-style-type: none">1. Case studies on laterality, family relationships, and pain revealed themes such as the need to define goals, identify content, and assess methods.2. A conceptualization of a harmonized Foundation was developed, outlining four levels of content harmonization: logical consistency, domain semantic integrity, cross-classification linkage, and semantic integration. The concept of Foundation Plus was introduced to describe relationships with other terminologies.3. A mapping project linked ICF Body structures and ICHI Targets to ICD-11 Anatomy codes using custom software and expert validation. This process provided insights into harmonization challenges and potential anatomy hierarchies.4. Use cases of cross-classification linkages were examined, including ICF core sets and U.S. Social Security Administration criteria. Finding no clear benefit for cross-classification linking, four criteria for such linkages were established.5. An inventory of overlap areas was created through a comprehensive scan of the three classifications. This involved horizontal and vertical evaluations, resulting in a typology of overlap areas.6. Methods for harmonizing overlap areas were explored using OWL axioms in the Protege environment.7. The implications for the update process were examined, noting that the current classification-centric approach will require new types of update proposals, new workflow, and expert knowledge combinations to address harmonization and post-harmonization change proposals. <p>A report summarizing all areas of work is being prepared.</p>	<p>With the iCAT-2 team starting re-engineering of iCAT-2, it is an opportune time to add appropriate representation for linked or imported terms from external ontologies. WHO staff, and members of ITC, iCAT-2, and the Monarch Initiative teams met in May to discuss concrete steps to achieve the integration of ICD-11 Foundation and Mondo. The Monarch Initiative has released the first version of the Mondo Disease Ontology that includes entities from the ICD-11 Foundation. Use cases involving genomic variants and Faconi anemia have been suggested as the vehicles for investigating how the Foundation can be extended to includes entities from external ontologies.</p>
<p>Platforms, Software Tools and APIs for WHO-FIC</p> <p>The 2024 version of ICD-11 was released in January, with Czech, Portuguese and Uzbek added to the existing languages of Arabic, Chinese, English, Spanish and French, Russian and Turkish.</p> <p>2024 release included ICF which is the first release of ICF after it is merged into the Foundation. This allows us using all of our modern tooling such as iCat, Coding Tool, Browser, Proposal System, Translation tool and APIs for ICF as well.</p> <p>DORIS 1.0.0 released with enhanced rules. Together with it, we released a new version of Doris Desktop, the offline version for DORIS, which contains enhanced data management features and much better user interface than the earlier versions.</p> <p>CodeFusion, an offline tool for automatic coding of textual diagnostic phrases is made available to the WHOFIC Network. https://icd.who.int/docs/codefusion/en/</p> <p>A pre-release for the updated version of the FHIR support for ICD-API is made available for interested parties</p>		<p>Terminology Mappings Software</p> <p>To reduce the burden of manual mapping between ICD-10 country modifications and ICD-11 and between SNOMED CT (SCT) and ICD-11, we plan to evaluate several terminology mapping or ontology-alignment tools against a collection of reference maps. These reference maps include two sets of ICD-10-CM-to-ICD-11 maps from US NLM, ICD-10-to-ICD-11 maps from WHO, and the SCT/Foundation maps created by the SNOMED International/WHO pilot mapping project. We may also have access to the Canadian CC's ICD-10-CA-to-ICD-11 maps if legal questions can be resolved. The Dutch CC is funding the time of a scientific programmer to assist with the project. A private software repository has been set up to collect all necessary materials. An advisory team and a development team are in place. The necessary pipelines to run the software (CodeFusion, LexMatch, LogMap 2.0, AgreementMakerLight, LLM like GPT, OnAGUI, and String_grouper) on these data sets and compute various evaluation metrics are being developed. We expect much of the work to be completed and reported before the October Annual Meeting.</p>



MRG ANNUAL REPORT 2023-2024

14-18 October 2024

WHO-FIC

Poster Number
105

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Abstract The Mortality Reference Group (MRG) comprises members from WHO FIC Collaborating Centres and regional offices, with a work program focused on advising on the mortality application of the ICD. In its 26th year, the MRG work program was mostly focused on supporting the transition from ICD-10 to ICD-11 with respect to mortality data.

Introduction

This is the 26th annual report of the Mortality Reference Group (MRG), established at the 1997 meeting of the Centre Heads as part of an updating mechanism for ICD-10.

ICD-11 was adopted by the WHA in May 2019. As such, the MRG’s main focus has been on supporting the implementation of ICD-11 throughout 2023-2024. This report describes the background of the MRG and its activities in the 26th year.

Methods & Materials

Provisions for the MRG are described in the conduct paper of the WHO-FIC network([conduct-of-the-who-fic-network.pdf](#))* where its objective is to improve international comparability of mortality data by establishing standardized application of the ICD. The MRG was one of the first groups WHO – working with the Centre Heads - established for updating ICD-10 and continues its role with ICD-11. The MRG discusses issues raised in the Mortality Forum or those referred from other sources including the Centre Heads and WHO. The MRG can make decisions regarding the application and interpretation of ICD to mortality and submit a subset as recommendations to the CSAC for a vote on ICD updates and changes.

* See also WHO long-term strategy document (WHO/HST/ICD/ C/97.39) and the Centre Heads’ Report for 1997 (WHO/HST/ICD/C/97.65).

2023-2024 Meetings

Type	Date
Monthly	December 14
Monthly	February 1
Monthly	March 14
Monthly	April 11
Mid-year, Mexico City	May 13-16
Monthly	June 13
Monthly	July 11
Monthly	August 15
Monthly	September 12

In addition to face-to-face meetings, the MRG continued to hold monthly virtual meetings to try to better progress key topics.

MRG Workplan

- **Assessing proposals and/or putting forward proposals for updates to ICD-11**
- **Mapping of ICD-11 with direction from the mapping task force**
- **Coding, tabulation, and reporting issues**
 - Provide advice on coding issues/decisions
 - Advise on tabulation lists
 - Prepare for bridge coding exercises
- **Automated coding tools**
 - Support efforts to develop automated coding tools
 - Provide input into development of revised decision tables
 - Prepare and code test datasets as required
- **Data storage, structures, and metadata issues**
 - Consider data structure, storage, analysis and reporting mechanisms
 - Consider IT implications of managing new ICD-11 structures



MRG achievements, operations and plans

In 2023-2024, the MRG continued ongoing discussions, entertained many issues and proposals referred to the MRG by other groups, and organized issues into themes as part of the MRG work program.

MRG Priorities

1. Highest:
 - Resolve outstanding issues in the classification
 - Resolve outstanding issues in the reference guide
 - Provide practical guidance for coding mortality data
 - Provide guidance for representing and analysing mortality data
2. Moderate:
 - Agree policy on differences between coding tools
3. Lowest:
 - Share ideas and experience on implementation

Major topics discussed in MRG

- ✓ ICD-11 implementation
- ✓ Current needs (e.g., 2019 updates to be reflected in ICD-11; upgrades to coding tool and API; better mapping tables)
- ✓ Identify, assess, and understand how to find, use, or follow better (e.g., syntax; reference guide; terms)
- ✓ Coding exercises
- ✓ Proposals (e.g., SIDS and perinatal; neoplasms; external causes; not to be used instruction; maternal mortality; infections; M2 instructions; late effect of stroke)

Upcoming milestones

The MRG is expecting to receive queries from Member States as they begin ICD-11 mortality coding. As such, the MRG is working to anticipate and to be ready to respond to queries as they arise. The MRG also wants to be in a position to provide strong advice around use of ICD-11 that will maintain international consistency as countries adopt the classification.

Conclusions

The MRG has dealt with many issues related to updating and clarifying ICD as it applies to mortality classification and coding. Such work continues as countries move toward implementation of ICD-11. So far, attention has focused on transition topics related to the content of the Reference Guide, coding exercises, and aspects of implementation.



Morbidity Reference Group Annual Report 2024

14-18 October 2024

WHO-FIC

Poster Number

106

Authors: M. Zvolský¹, M. Vikdal², K. Mabon³¹ Institute of Health Information and Statistics of the Czech Republic² Code systems dept., Norwegian Directorate of Health³ Canadian Institute for Health Information

Abstract This poster presents the purpose and work performed in the Morbidity Reference Group, highlighting activities undertaken during 2023-2024.

Introduction

The Morbidity Reference Group (MbRG) identifies, discusses and provides guidance related to interpreting and applying the ICD to morbidity coding and classification.

MbRG supports WHO and the WHO-FIC Network by providing input and advice for development and use of the ICD-11 for morbidity purposes, and the work of other WHO-FIC reference groups and committees where needed.

Activities and achievements

The following work and meetings have been conducted the last 12 months, along with several virtual meetings on selected topics.

October 16th 2023

The Annual WHO-FIC meeting in Bonn

Three 75-minute, hybrid sessions were chaired by Keith Denny and Miroslav Zvolský, with Kristy Mabon as secretariat. Keith Denny stepped down as MbRG co-chair after he was elected as co-chair of the WHO-FIC Council the same day. Nominations for a new co-chair were received, and Marie Vikdal was elected as co-chair in November 2023.

The main topics of interest and discussion were:

- The newly released WHO Value Set Domain Platform
- The joint work between Orphanet and WHO on rare diseases in ICD-11, and practicalities for use.
- Use of and engagement with the ICD-11 Implementation forum (w/EIC)
- ICD-11 descriptions maintenance
- Principles for use of ICD-FiT in coding exercises, exemplified by cancer coding and inclusions of translations
- Considerations around the different national needs and linearizations in ICD-11 morbidity coding
- Updates on the use of ICD-11 and ICHI to create an international case mix tool, and the Quality and Safety Working Group

Review of annual work plan :

The following priorities were identified:

- **Follow up on cancer coding with small working group:**
 - Complete answer key for exercise 2
 - Complete guidance for Reference Guide
 - Enhanced functionality for coding tool
 - Follow up from Spanish coding exercises
- **Consider the need for additional coding exercises:**
 - Injuries (identified at mid-year meeting)
 - Obstetrics (identified at mid-year meeting)



Virtual and on-site participants in the Morbidity Reference Group's mid-year meeting in Mexico City May 13-14 2024

- **Guidance on use of URIs (e.g., for rare diseases and national linearizations)**
- **Other possible follow-ups:**
 - Descriptions maintenance in ICD-11?
 - Support for development of international DRG?
 - Continue discussion about national use of ICD-11?

May 13th and 14th 2024

The Mid-year meeting in Mexico City

Two full day, hybrid meetings were hosted by the Mexican Collaborating Centre.

Progress on the annual work plan:

- **Input collected on the WHO-videos at Youtube**
- **Cancer coding in Reference Guide finalized**
- **ICD-FiT, Coding Exercises in obstetrics and injuries**
 - MbRG members completed two sets of coding exercises and identified several update activities needed in the Reference Guide, coding tool, and WHO-FIC/ICD-11 Foundation.
 - MbRG members agreed that the coding exercises in ICD-FiT should hold answer keys both with and without extension codes.
- **Updates to Reference guide:**
 - Proposals from CSAC to the Reference Guide updates was reviewed by participants before the meeting and briefly and discussed.
 - The Quality and Safety Working Group proposals will review the content specific to Q&S.
- **Develop guidance for national linearizations**

Questions were presented by Keith Denny for discussion in the meeting, that identified the following activities:

- Members requested more information about the content model and a demonstration of how a national linearization could work.
- WHO requests detailed examples of country's specific needs to demonstrate 'how' a particular concept could be elevated into a national linearization.
- **The need for a close coordination between MbRG and MRG** for several coding topics in ICD-11.

Pending topics and activities

- **Descriptions maintenance in ICD-11** Draft paper shared with WHO by M. Zvolský to for feedback.
- **Increasing use of and engagement in the ICD-11 implementation forum** Governance and maintenance is the responsibility of EIC, but there are opportunities to increase participation by members.
- **International case mix tool**
- Progress is currently monitored by WHO and to be presented in the 2024 Annual meeting.
- **Engagement in ICD-11 topics for presentation in congresses** M-Zvolský prepared and with contributions from the WHO Team and colleagues submitted a paper on Rare disease coding for EFMI Special Topics Conference in November 2024

Acknowledgements

The co-chairs and secretariat wish to acknowledge the work of the MbRG members and collaborating centres for their contributions over the past year, and also to former MbRG co-chair Keith Denny for his continuous contribution during the period.



FDRG ANNUAL REPORT 2023-2024

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Abstract

This report outlines the activities of the Functioning and Disability Reference Group (FDRG) over the past year, from 2023 to October 2024, as part of the Strategic Work Plan. These initiatives were carried out during the WHO-FIC annual meeting, regular teleconferences, the midyear meeting in 2024 in Mexico City, and joint sessions with FDRG/EIC and CSAC-ICF in Mexico, as well as through collaborations with other technical groups.

Introduction

As part of its Strategic Work Plan (SWP), the Functioning and Disability Reference Group (FDRG) aims to provide expert guidance and input for the development and application of the WHO-FIC in the context of functioning and disability. This effort ensures that these classifications are effectively utilized to generate reliable national and international statistics on functioning, disability, and health. The objective also encompasses the promotion of tools such as the WHO Disability Assessment Schedule (WHODAS 2.0) and other instruments aligned with the International Classification of Functioning, Disability, and Health (ICF) framework. By doing so, FDRG seeks to optimize the use of ICF and strengthen its integration with other WHO-FIC classifications, enhancing the overall quality and coherence of health information systems.

As part of the ongoing efforts to integrate and modernize ICF, the FDRG has been actively engaged in several key initiatives.

ICF Terminology Enrichment

A pilot project was initiated to test the feasibility of automatically translating clinical records into ICF codes. Beginning with English datasets, descriptive texts linked to ICF codes were identified, and frequently associated terms were extracted. A comprehensive table was created to organize information on available datasets for functioning descriptions and coding. Machine learning and natural language processing were employed to extract meaningful terms, followed by expert manual curation for refinement. This process included a detailed review of over 1300 ICF categories, with lay language descriptions provided for 800 of them. The project involved consensus-based categorization and experimental group work to ensure accuracy.

Acknowledgements

The contributions and active participation of all FDRG members around the world have been instrumental in achieving our objectives across all areas. Engagement during virtual sessions, consistent follow-up, and in-person meetings have been vital in advancing and strengthening the work of the FDRG.

Content Alignment and Harmonization

Significant progress was made in aligning the anatomical classifications of ICF with ICD-11. Challenges included inconsistencies in macro-structures, hierarchical differences, and the positioning of transition regions. After extensive mapping and discussions, solutions were proposed, though resource limitations remain a concern. Despite suggestions to remove body structures from the ICF and rely solely on ICD, the consensus was to retain them due to their importance in certain contexts. The harmonization work also highlighted the need for continued collaboration to address these challenges.



Language Translation and ICF Coding Tool

Translations of the ICF into Czech and Turkish have been completed, with further expansions planned. The translation platform supports multiple languages, although issues such as potential misinterpretations in Spanish were noted. A translation cycle is being established to keep pace with ICF updates. The ICF coding tool was also discussed, with strong support for ensuring visibility of first and second-level categories.

CSAC-ICF Activities

During the last year, the activities of the ICF CSAC were presented, including a summary of the proposals that have been decided upon as well as those still under consideration by the FDRG. In light of the outcomes from the harmonization and terminology enrichment efforts, it was acknowledged that a significant number of update proposals with specific characteristics will emerge. These proposals will require a tailored evaluation process to ensure they are thoroughly and appropriately reviewed.

ICF Reference Guide and Terminology Updates

The FDRG reviewed proposals for terminology updates, emphasizing the need for a specialized evaluation process. Agreement was reached to use letter-based qualifiers in the ICF coding tool and to align coding practices with the ICD-11 V-section. Qualifier Identification: It was unanimously agreed that letters should be used to identify qualifiers, as presented in the coding tool. This approach will standardize qualifiers as follows: qp, qc, qb, qf, qm.

Code Levels in the ICF Coding Tool: The group agreed that all code levels must be accessible within the ICF coding tool. The appropriate level of coding should be determined based on the specific purpose of the health information being recorded.

Unified Coding for Activities and Participation: The decision was made to eliminate the option to code Activities (A) and Participation (P) separately, as previously stated in the ICF manual. This aligns with current coding practices.

All this work was conducted through four full teleconferences and small group session and mid-year meeting. Additionally, there was participation in the EIC, FDC, and CSAC-ICF meetings.





The Mapping Task Force

14-18 October 2024

WHO-FIC

Poster Number
108

Sharon Baker¹, Samson Tu², Alana Lane¹, Eva Krpelanova³ and
Members of MTF

CIHI and Canadian CC, Canada¹, Stanford University CC, USA¹, WHO³

Abstract The Mapping Task Force (MTF) was created in 2023 to coordinate and advise terminology mapping-related activities within the WHO-FIC Network. In 2024, MTF focuses on 1. the validation of the WHO ICD-10-to-ICD-11 mapping table, 2. a questionnaire to assess the mapping needs and activities (especially regarding ICD-10 country modification mappings to ICD-11), and 3. an evaluation of automated mapping tools using reference maps from different sources.

Introduction

The Mapping Task Force (MTF) was created in 2023 to coordinate and advise terminology mapping-related activities within the WHO-FIC Network. In 2024, MTF focuses on three tasks: 1. the validation of the WHO ICD-10-to-ICD-11 mapping table, 2. a questionnaire to assess the mapping needs and activities (especially regarding ICD-10 country modification mappings to ICD-11), and 3. an evaluation of automated mapping tools using reference maps from different sources. Details of these three tasks can be found on their own posters at this meeting. We present an overview of the work here.

Methods & Materials

1. A subgroup of MTF designed the protocol and tools for teams of mapping specialist reviewers contributed by various collaborating centres to review a collection of ICD-10-to-ICD-11 maps where Canadian Institute of Health Information (CIHI) mappers disagreed with the same entries in the mapping table developed by WHO. A reconciliation process is implemented to adjudicate disagreements among reviewers
2. The co-chairs of MTF iteratively developed the questionnaire items with inputs from members of MTF. Several MTF members test-drove the questionnaire before it was distributed to heads of WHO-FIC collaborating centres in November 2023. A report has been written summarizing the responses from the centres.
3. A preliminary study using the WHO ICD-10-to-ICD-11 mapping table as a reference set established the feasibility of the project. In addition to the WHO mapping table, the National Library of Medicine (NLM) in the United States provided two ICD-M-to-ICD-11 mapping reference sets and the results of the SNOMED-CT/ICD-11 pilot mapping project were made available to us. As software to be evaluated, we select CodeFusion, LexMatch, LogMap2.0, AgreementMakerLight, OnAGUI, String_grouper, and BERTMap, as well as the large language model GPT.

Results

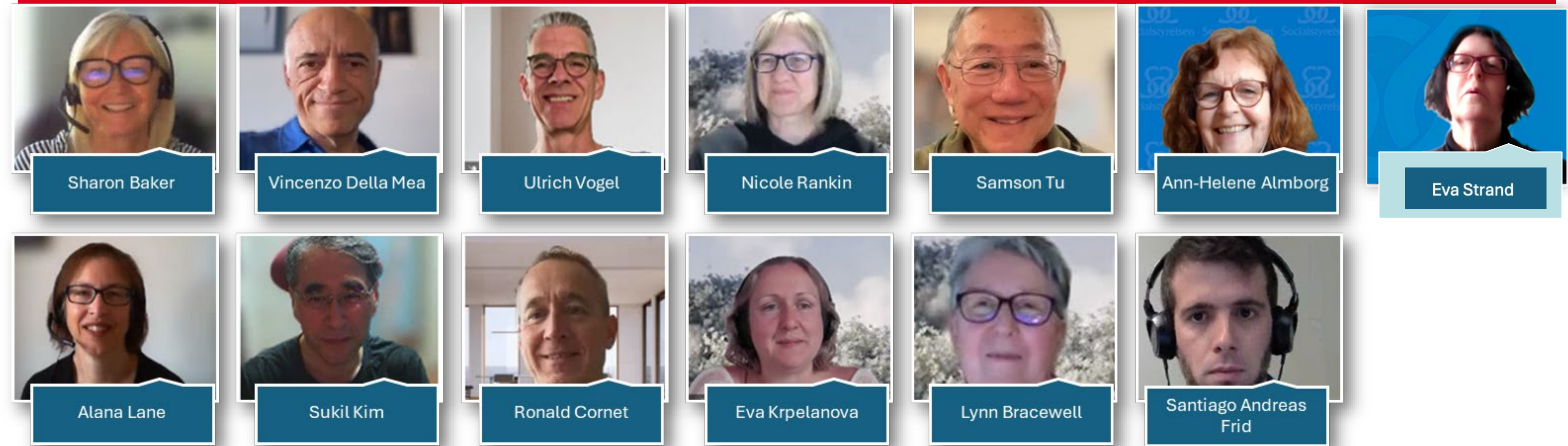


Figure 1. Members of the Mapping Task Force in 2024. Dr. David Berglund from the US is an additional member not pictured.

1. There are approximately 2,700 'no match' maps where the CIHI reviewers disagree with WHO's ICD-10-to-ICD-11 mapping table entries. The MTF validation work is still ongoing. Of the 488 maps reviewed, 303 had reviewer consensus with 94% (n=285) agreeing CIHI map is correct, 4% (n=13) agreeing with WHO map, and 1% (n=5) agreeing that neither was correct. Of the 185 maps that were reviewed for conflict resolution, 34% (N=62) were resolved for CIHI map correct, 12% (n=23) were resolved for neither was correct, 8% (n=14) were resolved that the WHO Map was correct, and 46% (n=86) were identified as requiring further discussions with WHO before resolution was identified. It is notable that close to half of the 488 maps reviewed involve residuals.
2. As of 1 August 2024, we received 17 responses from collaborating centres. The current ICD-10 country modifications to ICD-11 mapping work in different countries are mostly uncoordinated. They are at varying stages of development: some have not started, some have mapping work in progress, and some have completed phases of the work. Validated WHO ICD-10/ICD-11 mapping tables are the most urgent mapping needs of the respondents. Additional mapping needs include assistance with tooling and complex mappings and shared guidance. Several countries indicated that they are interested in mappings involving SNOMED CT and Orphanet.
3. At the time of making the poster, we had successfully run six of the mapping software we intended to evaluate on all four of our data sets. BERTMap turned out to require more computing power to train and fine-tune than what team members have access to. True positive and false negative rates have been computed for the outputs of the software using the WHO ICD-10-to-ICD-11 mapping table as the reference standard. The results show that CodeFusion can produce map targets for all of the map sources while LogMap 2.0 and AgreementMakerLight have high true positive rates in the 80% suffer from relatively high false negative rates (38.50 and 45.79). These results suggest that complementary uses of these tools may be feasible. A limitation is that the WHO ICD-10-to-ICD-11 mapping table as the reference standard may have a significant number of problems.

Discussion

In the questionnaire distributed to the collaborating centres, we asked them about the roles that MTF can play to help their work. The three workstreams that MTF has been focusing on this year, as described in this poster, match some of the roles indicated in the questionnaire responses. Additional roles include identifying similar mapping needs across the network, developing shared mapping guidance, reducing duplication of efforts, sharing mappings between ICD-10 country modifications and ICD-11, and coordinating the development of the Foundation, In the future, MTF may take up projects to satisfy these needs. For example, we can develop a standard format and guidance for country-modification mappings and a repository of shared maps resulting from these national mapping projects. Such projects would build on MTF's current work and help fulfil the mission of MTF.

Abstract Quality and Patient Safety Working Group (formerly the TAG) was assigned the task of identifying practical improvements for ICD 11 to facilitate more accurate measurement of quality and safety in healthcare. AThe current objectives of the group include developing new indicators for implementation in ICD-11, exploring the application of ICD-11 for quality and safety purposes, and providing support and education on coding concepts related to quality and safety.

Acitivites	Acitivities	Future Work
<ul style="list-style-type: none">Developing an inventory of existing quality of care & patient safety indicators and potentially novel quality and safety indicators.Assessing potential uses of ICD-11 for health services, quality & patient-centered outcomes research.Producing knowledge translation around ICD-11Examine Implementation of ICD-11 in adverse reporting systems	<p>Meetings:</p> <ul style="list-style-type: none">Virtual meetings <p>Topics:</p> <ul style="list-style-type: none">Update on PSI algorithmsDissemination and implementation of the innovations to capture quality and safety data through ICD-11 as well as stakeholder engagement (i.e., coders, otologists/ classification experts, hospital administrators, health services researchers, etc.). 	<ul style="list-style-type: none">Dissemination & implementation:Emphasis of meetings activities focused on strengthening stakeholder & user engagement.Academic articles in <i>BMC Medical Informatics and Decision Making</i>. In addition, the group has plans to work on dissemination appropriate for stakeholders at the decision-making levels.https://bmcmeginformdecismak.biomedcentral.com/articles/supplements/volume-21-supplement-6
Meetings		
<p>2023/24 Meeting Attendees</p> <p>Harold Pincus (Co-Chair, Columbia University); William Ghali (Co-Chair, University of Calgary/ Canada and Co-Chair WHO Morbidity Committee); Patrick Romano (University of California Davis); Oluseun Atolagbe (University of California Davis); Hude Quan (University of Calgary/ Canada); Alan Forster (Ottawa Hospital/ Canada); Chris Chute (Johns Hopkins University/ US); Sharon Baker (CIHI/Canada); James Harrison (Flinders University/ Australia, Chair of Injury and External Causes TAG); Marilyn Allen/Brandon Hoffman (American Acupuncture Council/ Member of Traditional Medicine TAG); Danielle Southern (University of Calgary/ Canada); Saskia Droesler (Niederrhein University of Applied Sciences/ Germany); Jean-Marie Januel (EHESP/ France); Marie-Annick Le Pogam (University of Lausanne/ Switzerland); Bastien Boussat (CHU/France); Cathy Eastwood (University of Calgary); Monika Ray (UCDavis)</p>	 	<p>Dissemination & implementation:</p> <p>Emphasis of meetings activities focused on strengthening stakeholder & user engagement.</p> <p>Academic articles in <i>BMC Medical Informatics and Decision Making</i>. In addition, the group has plans to work on dissemination appropriate for stakeholders at the decision-making levels.</p> <p>https://bmcmeginformdecismak.biomedcentral.com/articles/supplements/volume-21-supplement-6</p>
		Acknowledgements or Notes
		<ul style="list-style-type: none">Q&S TAG was funded by the Agency for Healthcare Research and Quality (AHRQ), Canadian Institute of Health Canadian Patient Safety Institute (CPSI), and Canadian Institute for Health Information (CIHI). Current meeting funds have been funded through the Canadian Institutes of Health Research (CIHR).



Verbal Autopsy Reference Group Annual Report 2023-2024

14-18 October 2024

WHO-FIC

Poster Number
110

Authors: Leitao J, Cobos D, Nichols E
VARG Secretariat; SwissTPH, VARG Co-chair; CDC, VARG Co-chair
WHO Liaisons: Robert Jakob, Carine Alsokhn

Abstract Verbal autopsy (VA) is a method used to determine the cause of death through interviews with the deceased person's next of kin or caregivers. These interviews involve a standardized questionnaire to gather details on symptoms, medical history, and the events leading to death. The collected information is then evaluated by healthcare professionals or algorithms to ascertain the probable cause of death. VA's main purpose is to capture cause-of-death data at the population level in areas with limited medical certification of deaths, aiding countries in enhancing their civil registration and vital statistics systems. This, in turn, informs evidence-based health policy-making and planning. The WHO Verbal Autopsy Reference Group (VARG) supports and advises WHO regarding development and maintenance of VA standards, respective instrument and associated processes including use of VA cause of death data to ensure consistency with ICD classification rules. The VARG also supports users in the implementation of VA. This poster presents a summary of the work undertaken by the VARG, highlighting activities and achievements from October 2023 to October 2024.

Introduction

- As VA becomes increasingly part of routine mortality data collection systems, the VARG supports and advises WHO regarding:
- Development and maintenance of WHO VA standards;
 - Standards and recommendations for VA training and implementation;
 - Advancement of methods and tools for assigning causes of death from VA interviews;
 - Use of the causes of death data determined by VA;
 - Use of the VA causes of death data as a complement to medically certified cause of death data;
 - Quality assessment and management of VA data; and
 - Methods for comparing and evaluating VA results.

Methods & Materials

- Activities have been carried out through three modalities:
- Dedicated working groups collaborating online under the coordination of VARG workstreams;
 - Monthly VARG coordination meetings; and
 - Virtual quarterly full VARG meetings.

- Five workstreams decentralize work structure to facilitate collaboration.**
- Questionnaire improvement & maintenance;
 - Develop and maintain resources & guidance;
 - IT developments and cause of death analysis;
 - User engagement;
 - Develop & support VA research agenda.

WS1 Questionnaire Improvement & Maintenance

- Official translations of the 2022 WHO VA Instrument being verified by the WHO VARG in 5 languages: Arabic, French, Portuguese, Spanish and Swahili.
- Feedback and issues reported from the field use of the 2022 WHO VA instrument and supporting training materials have been identified,

- catalogued, reviewed and addressed by the VARG.
 - Interfacing with users and VARG members to address data collection and data management aspects.
- VA COD list has been updated to be in line with ICD-11, and is now integrated within the ICD-11 reference guide annex and value set platform.

WS2 Develop and Maintain Resources & Guidance

Stages of Development	Guidances
In development phase	<ul style="list-style-type: none">• Quality management of VA implementation in CRVS settings• Managing ethical and sensitive issues for VA implementation in the context of CRVS
In review phase (e.g., full VARG/WHO/ external reviewers)	<ul style="list-style-type: none">• Set of reference media resources on VA signs and symptoms to supplement training materials• Cause of death assignment by physicians from VA data• VA and MCCD
In editorial phase	<ul style="list-style-type: none">• Update to the ODK Quick Guide
Finalized & published	<ul style="list-style-type: none">• WHO VA Standards Manual (minor updates)• VA Field Interviewer Manual (minor updates)

WS3 IT Developments & Cause of Death Analysis

- Tracking progress of the elicitation and validation of new probbase for 2022 instrument
 - Probbase update protocol finalized
 - Blank probbase aligned with the 2022 instrument and cause list
 - Relevance assessment of each probbase value through physician consultation
 - Customized online survey tool created and debugged for elicitation
 - 50-60 physicians onboarded
- Training materials created for the physicians

- Reference architecture and Digital Adaptation Kit for VA/IT systems ready for the review and approval of the VARG.

WS4 User engagement

Continued expanded engagement with VA implementation community

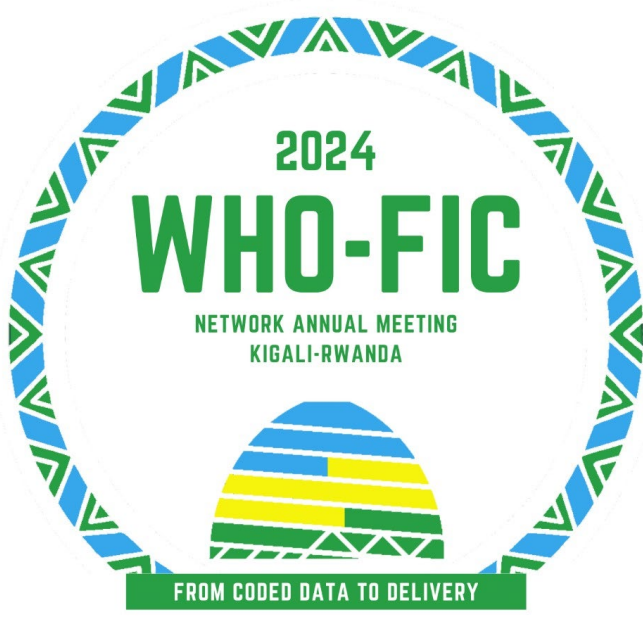
- VA community of practice regularly engaged through monthly webinars, increasingly led by implementing teams outside the VARG.
 - Webinars presented in English, French, Spanish, and Portuguese and are archived for later download on the WHO Collaborating Center for VA website.
- Web surveys of community of practice members as well as VA implementing institutions used to maintain an interactive global map of the type and distribution of VA implementations on the WHO VA standards website.

WS5 Develop & support VA research agenda

- Maintenance of a VA Implementation Literature Alert Service for a quarterly annotated bibliography of selected relevant evidence for VA for the VARG and the VA community of practice.

Acknowledgements

We would like to thank all members of the VARG, collaborating centers and partners for their commitment and contributions to the maintenance and advancement of VA standards, especially the dedicated working groups.



Medical and Scientific Advisory Committee Contributions in the year 2024

14-18 October 2024

WHO-FIC

Poster Number
111

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Abstract The Medical and Scientific Advisory Committee (MSAC) provides medical and scientific advice on changes or enhancements to the ICD-11, particularly in response to proposals received via the ICD-11 maintenance platform, or requests from the Classifications and Statistics Advisory Committee (CSAC), and associated reference groups. MSAC may also recommend changes or enhancements to ICD-11 based on scientific advances or other new information.

Introduction

The MSAC was launched at the ICD Revision Conference in 2016 and is comprised of 20 experts selected by WHO, some of whom were drawn from the Topic Advisory Groups. In addition, the co-chairs of CSAC sit as ex-officio members.

The primary role of the MSAC is to advise WHO on medical and scientific updates to ICD-11. This reduces initial pressure on national experts to review proposals, while still allowing for that input in the second step, thereby accelerating the implementation and maintenance of the classification by streamlining the process. It allows for scientific reflection of important medical innovations in the classification, in a timely fashion.

The MSAC met in hybrid format during the annual WHO-FIC Network meeting in 2023. During the period between November 2023 and September 2024, the MSAC met 10 times via videoconference. The main focus of the meetings has been on the review and consideration of proposals submitted via the ICD-11 maintenance platform.

Methods

The MSAC reviews proposals on the scientific merit including published evidence and international cross-disciplinary consensus, before a new entity can be added to or deleted from the ICD foundation. The MSAC will also evaluate proposals for entity descriptions and may be asked to participate in the review of changes to coding rules.

Proposals are initially assigned to a specific MSAC member for scientific review. Where possible, these are assigned according to specialty, but all members are experts in research methodology. If the topic relates to a specialty not represented on MSAC, members may consult with colleagues or external experts for the review. The introduction of a consent agenda has facilitated an effective proposal reviewing process.

Other issues discussed

The MSAC consent agenda review process was revisited and fully digitalized on the ICD-11 maintenance platform starting 2022. Since then members have a more efficient review mechanism, and communication of information to other WHO-FIC committees and reference groups as well as a mechanism to inform the general public.

Streamlining of the process of MSAC has been in discussion for further efficiency. The new feature on the ICD-11 Maintenance Platform to identify package proposals will facilitate the ongoing work when multiple proposals need to be reviewed, discussed, and voted on together.

The proposal addressing the expansion of restructuring of the organ donor area has been discussed further to develop a track change document for details, the work is ongoing.

- Proposals about genetically-determined epidemolysis bullosa

Based on consensus paper, MSAC was convinced about the evidence that led to considerations for ramifications in the parenting relationships, and determination of hierarchical consequences. A proposal was submitted as MSAC, accordingly (#2W3F).

- Expansion of the specialty of MSAC members

There were two new members that had joined this year, from the field of neurology, from Asia and South America. We hope to expand our specialties further so that reviewers will be assigned proposals of their exact field of expertise.

- Large-scale modification mechanism for Foundation enrichening and alignment with other classifications and terminologies

MSAC has been discussing the need of forecasting consequences of increasing foundation at scale, along with partnerships such as MONDO and Radlex.

Conclusions

MSAC recommendations are added to the proposal platform to ensure transparency of the maintenance process, and to inform CSAC members.

Acknowledgements

The MSAC Co-chairs and Secretariat, would like to thank all contributions made by experts, including the MSAC general membership, for their valuable contributions to the ongoing development and maintenance of the ICD-11. The resignation of MSAC member Professor Gerold Stucki, and Melissa Selb, from Swiss Paraplegic Research, is to be commemorated – their contributions are to be highly appreciated over the years.

Proposals referred in 2024

Total		128
Reviewed/ discussed		60
Decided	Total	54
	Accepted	18
	Accepted with modification	19
	Rejected	11
	Back to author	6