# IFHIMA Fosters Planning for ICD-11 Adoption with Global Case Studies

**IFHIMA**

International Federation of
Health Information Management Associations

# IFHIMA Fosters Planning for ICD-11 Adoption with Global Case Studies

## IFHIMA

### International Federation of
### Health Information Management Associations

**About IFHIMA**

The International Federation of Health Information Management Associations (IFHIMA) is a non-governmental organization (NGO) in official relations with the World Health Organization (WHO). The Federation acts as the global voice of the health information management profession, supporting the importance of education and training, high quality health data, and privacy of health information. IFHIMA is committed to the advancement of health information management practices and the development of its members for the purpose of improving health data and health outcomes.

- Would you like to keep informed on IFHIMA?  Sign up here.

- Did someone kindly share this whitepaper with you? You can get your own digital copy here as a free download.

- Yes! You may share – reprint with permission when you use this citation:

  IFHIMA Fosters Planning for ICD-11 Adoption with Global Case Studies, Copyright International Federation of Health Information Management Associations (IFHIMA), January 2021, Reprint with permission.

## Introduction

Quality health information underpins all facets of healthcare policy, delivery system design, patient engagement, and economic advancement of health and healthcare. This information must be accurate, readily available, and understandable at many levels of the global health community. Additionally, the ever-increasing role of analytics, machine learning, and artificial intelligence requires accurate and timely data to meet its full potential in improving health outcomes and access to care, while reducing costs. Thus, it is timely and appropriate that the adoption journey of the International Classification of Diseases (ICD) Eleventh revision (ICD-11) is underway. The structure of ICD-11, along with its ability to integrate to electronic health record systems (EHR) will allow ICD-11 to meet the goals and needs of diverse national and global stakeholders.

Accurate and consistent coding of clinical data is one of the core practices of health information management (HIM) professionals. The International Federation of Health Information Management Associations (IFHIMA) supports national HIM associations and HIM professionals around the globe in this practice. Our vision, a healthy world enabled by quality health information, underpins the 2020-2025 IFHIMA Strategic Plan and activities embracing high quality, accessible health data.

The ICD-11 was formally adopted by the World Health Assembly in May 2019

In publishing this whitepaper, IFHIMA hopes to facilitate awareness and foster readiness within the global healthcare community for the implementation of ICD-11. IFHIMA recognizes that the stakeholders involved in planning and adopting ICD-11 are diverse, including policymakers, ministries of health (MOH), clinicians, health informaticians, epidemiologists, HIM professionals, and researchers.

IFHIMA acknowledges and commends the World Health Organization (WHO), its member organizations and particularly the Classifications and Terminologies Unit, Division of Data, Analytics and Delivery for Impact and the Family of International Classifications (FIC) Network for their development of the wealth of information, training, and reference materials available in support of the transition to ICD-11.

## Development of ICD-11

ICD-11 is a part of the suite of the WHO FIC which also includes the International Classification of Functioning, Disability and Health (ICF), as well as the International Classification of Health Interventions (ICHI). ICD's purpose is to allow for the systematic recording, analysis, interpretation, and comparison of mortality and morbidity data collected in different countries or areas and at different times.[1]

The WHO began developing ICD-11 in 2007. The process started by identifying issues with the structure of the ICD-10 classification and formulating possible solutions. Goals of the revision included updating the classification to better reflect progress in health sciences and medical practice in addition to better aligning it with advances in information technology.[2]

An on-line ICD-11 platform was created to support a broad range of input from clinical, scientific, technical, and HIM professionals specializing in classification development. Experts were invited to comment, submit proposals, and/or serve as appointed reviewers. In the latter stages of ICD-11 development, an ICD-11 Joint Task Force was created to provide guidance on content and to ensure that the overall structure of ICD-11 was consistent and usable.

A preliminary version of ICD-11 was released for WHO Member State comment at the ICD-11 Revision Conference in Tokyo in October 2016; the IFHIMA 18th Congress was held in conjunction with this conference. [3] Following this, focused field trials of the classification through WHO-FIC Collaborating Centers occurred in late 2016 and more extensive and specialized field trials continued during 2017.

Member State comments and feedback from these field trials and stakeholders were used by WHO to prepare a "fit-for-purpose" ICD-11 release for countries to begin preparations for implementation beginning June 2018. The ICD-11 was formally adopted by the World Health Assembly in May 2019 with international reporting utilizing ICD-11 commencing in January 2022.[4]

IFHIMA
International Federation of
Health Information Management Associations

## Content and Characteristics of ICD-11

ICD-11 has been updated for the 21st century and reflects critical advances in science and medicine through updated scientific content and enhanced clinical detail. It is fully electronic, though it can be used on-line, off-line, or even in printed format. The architecture of ICD-11 is different from previous versions of ICD as it is the first version that is specifically designed for electronic environments. ICD-11 includes an application program interface (API) that allows for real-time integration to electronic health record (EHR) systems, thus facilitating point of care data capture. Further, ICD-11, as developed by WHO, includes the Coding Tool which is a user friendly, searchable index of diagnoses. The underlying structure, the ICD-11 Foundation, is a large semantic database of all ICD concepts, codes and synonyms, including broad clinical concepts to very specific clinical detail.[5]

Historically, many countries have expanded on the WHO ICD version, adding clinical detail to meet their specific needs. This resulted in many parallel but inconsistent versions used worldwide, making international data comparability difficult. With the ICD-11 Foundation Component, it is hoped that countries instead use ICD as is or define a subset of codes from the Foundation (i.e., a linearization) for their specific use that is fully embedded in ICD-11.  The WHO has defined a linearization from the Foundation for Mortality and Morbidity Statistics (ICD-11 MMS). Additional specialized linearizations have also been defined, such as Primary Care, Traditional Medicine, and Dermatology. A country may choose to adopt the WHO's ICD-11 MMS as is or define a different linearization with additional detail to meet their specific data use needs.

ICD-11 features and their associated value are summarized below, and details can be found here, in the ICD-11 Implementation and Transition Guide.

| ICD-11 Technical Feature | Value |
|---|---|
| Multi-lingual Coding Tool and Browser | Supporting the multi-lingual Browser, the Coding Tool has built in coding instructions and provides countries, irrespective of language with a user-friendly searchable index to clinical concepts contained within ICD-11 |
| Multi-lingual assessment Tool | An implementation assessment tool, known as ICD-FiT, provides for the coding of diagnostic terms in both ICD-11 and ICD-10 for comparison and has the capability of testing translations in multiple languages |
| Web-based services | Supports different, common software versions used around the globe, saving time and money while supporting uniformity |
| On-line services | Saves time and expense (hardware, software, maintenance) of local software, ensures consistency and automatic updating |
| Off-line services | Allows offline use for organizations or countries who do not have consistent, stable internet or who desire offline use for select phases of implementation |
| Export and visualization | Output in variety of mediums including API supporting integration, visualization, aggregation and comparison of ICD-11 to ICD-10 |

IFHIMA
International Federation of
Health Information Management Associations

By contrast, ICD-11 contains 80,000 entities that point to some 17,000 codes in 26 chapters, compared to the 14,000 in 21 chapters in ICD-10. Notable changes to the chapters can be found in the ICD-11 Reference Guide.

> The design of stem codes ensures that in use cases that require only one code per case, a meaningful minimum of information is collected.

Similar to ICD-10, the codes in ICD-11 are alphanumeric and range from 1A00.00 to ZZ92.ZZ. The first character in a code identifies a chapter (either by number or letter). There are some major differences, however, including the coding scheme, meaning how the codes are structured. ICD-11 changes the three-character category codes (characters to the left of the decimal) to four with an alpha-character in the second position and number always in the third position. In ICD-11, there is a minimum of four characters and a maximum of seven compared to a minimum of three characters and a maximum of five in ICD-10. For example:

| Disease | ICD-10 Code | ICD-11 Code |
|---|---|---|
| Diabetes mellitus, Type 2 | E11.9 | 5A11 |
| Chronic kidney disease, stage 4 | N18.4 | GB61.4 |
| Disseminated cutaneous candidosis | B37.2 | 1F23.15 |

The code structure in ICD-11 includes stem codes and extension codes. Stem codes are codes that can be used alone. They are found in the tabular list of ICD-11 MMS and may be entities or groupings of high relevance, or clinical conditions that should always be described as one single category. Stem codes may contain all pertinent information about a clinical concept in a pre-combined fashion. This is referred to as 'pre-coordination'. For example, BD50.40 *Abdominal aortic aneurysm with perforation, or CA40.04*

*Pneumonia due to Mycoplasma pneumoniae.* The design of stem codes ensures that in use cases that require only one code per case, a meaningful minimum of information is collected.

In disease coding, extension codes (codes starting with an 'X') are designed to standardize the way additional information is added to a stem code when users and settings are interested in reporting more detail than is included in a stem code. Extension codes can never be used without a stem code and can never appear in the first position in a code cluster discussed below. For example, extension codes can indicate laterality; left - XK8G, specific anatomy; anterior wall of heart - XA7RE3, or simply to identify the discharge diagnosis as the main condition XY0Y or the main resource condition XY7B. However, in other use cases, e.g. for documentation of devices or active substances, or histopathology of tumors, stem codes may be used alone.

ICD-11 provides a mechanism for pre- and post-coordination. The concepts of pre-coordination and post-coordination in ICD-11 enable health conditions to be described to any level of detail by either one pre-coordinated stem code or by the use of more than one code by post-coordination to form a cluster of codes. Clustering involves the process of post-coordination of two or more stem codes or a stem code with one or more extension code(s).

The table below shows the proper syntax for ICD-11 post-coordinated code clusters. An ampersand (&) is used to post-coordinate a stem code with an extension code, while a forward slash (/) is used to post-coordinate a stem code with another stem code.

| Examples | ICD-11 Code Cluster | ICD-11 Code Titles |
|---|---|---|
| Acute ST elevation myocardial infarction, anterior wall | BA41.0&XA7RE3 | BA41.0 Acute ST elevation myocardial infarction (stem code)<br><br>XA7RE3 Anterior wall of heart (extension code) |

| | | |
|---|---|---|
| Chronic kidney disease, stage 4 due to Type 1 diabetes mellitus | GB61.4/5A10 | GB61.4 Chronic kidney disease, stage 4 (stem code)<br><br>5A10 Type 1 diabetes mellitus (stem code) |
| Left diabetic cataract in patient with Type 2 diabetes mellitus | 9B10.21&XK8G/5A11 | 9B10.21 Diabetic cataract (stem code)<br><br>XK8G Left (extension code)<br><br>5A11 Type 2 diabetes mellitus (stem code) |

More information on the changes from ICD-10 to ICD-11, including side-by-side comparisons and the rationale for the changes, is available in the ICD-11 Reference Guide, Part 3 New in ICD-11.[6]

## Benefits of ICD-11

Countries implementing ICD-11 will find multiple benefits including updated scientific knowledge, improved architecture to accommodate multiple use cases, intentional design for electronic health records (EHRs) and health information systems (HIS), as well as links to other relevant classifications and terminologies.

From an organizational and governmental perspective, implementing clinical coding in health organizations is essential to improving data quality. The benefits include reducing negligence and medical errors, supporting

ICD-11 includes over 80,000 entities demonstrating how medical knowledge and need of documenting clinical detail have grown since ICD-10 was released in 1992.

research, improving tracking of health services, managing health insurance, and more.[7] ICD-11 supports all of these and other purposes, among those notably is improved public health reporting and bio surveillance data.

As stated earlier, ICD-11 includes over 80,000 entities demonstrating how medical knowledge and need of documenting clinical detail have grown since ICD-10 was released in 1992. It provides access to 17,000 diagnostic categories, with over 120,000[8] medical diagnostic index terms, 80,000 concepts and over 1.6 million clinical terms interpreted. It contains up to date scientific knowledge and mechanisms that allow health information to be captured and measured on current health concerns such as antimicrobial resistance, newly discovered microbes (e.g., COVID-19), and patient safety to name just a few. This dramatic expansion will aid the many uses of coded morbidity and mortality data.

Additionally, the unique architecture of ICD-11, including the ICD Foundation and the ability to define a linearization, ensures that ICD-11 can support diverse uses. Historically, many countries have built upon the WHO ICD by creating their own code set (for example, Australia created ICD-10-AM, Canada created ICD-10-CA, United States created ICD-10-CM, etc.). However, with ICD-11, countries can define a specific linearization for their unique needs as opposed to creating a unique code set, thereby saving potentially years and considerable expense in the implementation. Or a country could simply adopt the WHO ICD-11 MMS linearization to accommodate the collection and reporting of mortality and morbidity statistics or one of the other linearizations developed and supported by WHO.

This ICD-11 architecture supports the ability to address diverse priorities of governments around the world. Additionally, the broad stakeholder community can readily use ICD-11 for the purposes of advancing population health, improving patient outcomes, enhancing patient care delivery, optimizing payment of healthcare services, and supporting the global reporting of mortality and morbidity data. Lastly, ICD-11 architecture readily supports creating new code sets as medical knowledge and technology advance and emerging infectious diseases are identified, thus providing better tools to alert countries and health officials.

Whether an organization or nation uses a proprietary or open source EHR, ICD-11 will be available to these systems through the ICD Application Programming Interface (API). ICD-11 also makes use of other electronic tools and platforms. The ICD-API supports each ICD-11 entity's Unique Resource Identifier (URI) and back-end web services to provide easy access to ICD content as well as facilitates links to external terminologies. These electronic enhancements will promote timely creation of coded data, and higher quality, consistent data aiding policymakers, researchers, and care delivery. Additionally, the many electronic features will aid in workforce training and development, as discussed in the case studies at the end of this whitepaper from Canada and the WHO/Eastern Mediterranean Region.

> HIM professionals, as individuals with real-world coding experience, provide a unique, valuable perspective in this initial step

Furthermore, the structure of ICD-11 facilitates ongoing coordination discussions between the WHO and SNOMED International (Systematized Nomenclature of Medicine—Clinical Terms), MedDRA (Medical Dictionary for Regulatory Activities), LOINC (Logical Observation for Identifiers Names and Codes, and HPO (Human Phenotype Ontology). Improved coordination between WHO and the other terminology systems will aid the stakeholders and use cases that share mutual goals for improved health data and health outcomes.

## ICD-11 Adoption and Implementation Strategies

The WHO has developed an ICD-11 implementation package to support the introduction and use of ICD-11 which includes the Classification System, the ICD-11 Browser, Coding Tool, Reference Guide, and the *ICD-11 Implementation or Transition Guide.* The ICD-11 Implementation or Transition Guide lists key recommended actions along with a timetable template to help support the implementation

process.[9] The recommendations outlined below complement the WHO implementation package and address issues that should be considered to ensure that ICD-11 meets global and national purposes as discussed throughout this paper.

The first step for any country is to form a national task force or committee of relevant stakeholders to guide adoption and implementation strategies. Stakeholders should include policymakers, MOH, health informaticians, HIM professionals, health system executives, payment authorities, epidemiologists, and researchers. HIM professionals, as individuals with real-world coding experience, provide a unique, valuable perspective in this initial step.

Developing an implementation plan should begin with a review of the current uses of ICD. Once uses are identified and explored, a crucial first step, then the task force can determine whether they will adopt ICD-11 MMS or define the need for a more specific linearization for their country and health system as defined below. This determination should be informed by thorough gap and impact analyses specific to current and future uses. The decision of whether to adopt the ICD-11 MMS or to need a national extension will have broad implications and determine the country's overall approach and required resources. The task force can then set goals, establish and assign tasks, and build a timeline for implementation. Integral to any implementation plan is an education and training program for diverse stakeholders. Sample initial activities from IFHIMA member nation countries can be found in the case study section of this whitepaper as well as through WHO regional offices and collaborating centers.

According to the WHO, health systems have six building blocks: 1. health service delivery, 2. health workforce, 3. health information systems, 4. access to essential medicines, 5. health systems financing, and 6. leadership and governance.[10]

The following sections explore key activities which may be conducted at various levels of health systems including government, private sector, or in a collaborative public-private approach. Applying these activities to a specific country or region and their respective health systems requires an understanding of health policy decision-making, healthcare funding and

IFHIMA
International Federation of
Health Information Management Associations

resource allocation. Considerable variance in the activities and approaches are expected given these factors, as well as other factors such as economic priorities, public health status, current level of digitization of health data, etc.

### Explore Current Uses of ICD

The first step in planning for ICD-11 is to identify all current uses of ICD. For countries who have implemented a previous version of ICD, the national task force should thoroughly and systematically explore both data capture and information reporting to uncover all uses of ICD. For example, at a minimum they should explore how mortality, morbidity, and notifiable disease data are collected and how such data is used or is reported. Examples of exploration are included in Appendix A. At each level – local, regional, national – all processes associated with the capturing, reporting, and use of ICD data should be documented.

> It is essential that the task force consider not only data reporting, health payments, and resource allocation, but also the multitude of other data uses.

For countries who have not previously implemented a version of ICD, the task force should identify and prioritize the desired ICD data capture and information reporting. It's important to develop a comprehensive list of current or potential use cases in order to clearly define the country's data needs.

It is essential that the task force consider not only data reporting, health payments, and resource allocation, but also the multitude of other data uses. These data uses may vary considerably based upon many factors including EHR adoption and technology maturity. Use cases of ICD data to consider include, but are not limited to:

- Mortality reporting on death certificates

- Capturing and reporting morbidity data

- Healthcare payment and medical expense systems

- Utilization and allocation of healthcare services

- Evaluation and planning of public health programs

- Assessing the value of and/or quality of healthcare services

- Patient safety initiatives, for example adverse event reporting

- Population health management, for example determining severity or risk levels

- Healthcare research

- Patient engagement initiatives to promote wellness

- Monitoring for an epidemic or other public health outbreak

As each of the use cases is explored and considered, the task force should confirm that the relevant stakeholders associated with each use case have been consulted, informed, and are sufficiently represented on the task force. In countries that tie healthcare payments and/ or health expenditures, or health resource allocation to ICD coded data, there is likely a specialized group of stakeholders that must be consulted including, government, health insurers, and technology vendors. Only with this thorough exploration and broad stakeholder input can an informed implementation decision be made.

Once all of the use cases have been identified, with input from the relevant stakeholders, the task force can proceed to evaluate ICD-11 specifically for the use cases. This gap and impact analysis may take the form of feasibility studies or pilot tests of ICD-11 as discussed in the case studies at the end of this whitepaper.

### Complete Gap and Impact Analysis

The next step in planning for ICD-11 is to evaluate how the ICD-11 MMS, or one of the other linearizations, will meet the particular data need for current or planned uses of ICD coded data. The task force may need to assign focused work groups to conduct use case-specific feasibility studies followed by pilot tests, where

appropriate. For those nations or regions using a previous version of ICD, the study must evaluate:

- Compare ICD-11 to the previous ICD version used by the country, comparing and contrasting the data

- Identify the gaps in the ICD data and use cases that may be addressed by ICD-11

- Identify gaps not addressed with ICD-11

- Explore future uses cases (understanding that all will not be known) and how ICD-11 will support data collection, reporting, and use

- Document and share with WHO any gaps or new uses for consideration to be added to the ICD-11 Foundation. The WHO provides a maintenance platform to submit proposals and comments on ICD-11[11]

In countries that tie healthcare payments, health expenditures, or resource allocation to ICD coded data, a thorough, focused assessment of the impact of moving to ICD-11 must be undertaken. This task is crucial as "About 70% of the world's health expenditures (USD $3.5 billion) are allocated using ICD for reimbursement and resource allocation."[12] This financially focused analysis is vital to the subsequent design, testing, and integration with numerous systems used by the stakeholders. For these countries such as Japan (as discussed in a case study following this whitepaper) the evaluation of how ICD-11 will be tied into a payment or resource allocation system may be a key determinant as to whether the country will adopt ICD-11 MMS or will instead choose to define their own linearization to specifically align with unique data used by the payment or resource allocation system.

Another consideration that may impact the exploration of use cases is the evolving health data privacy regulatory environment of a country. The IFHIMA whitepaper, Privacy of Health Information, an IFHIMA Global Perspective, explores governance and data privacy concerns that may be relevant.

The gap and impact analysis of each use case may take considerable time, especially for those countries where ICD is currently used for multiple and varied purposes. It is critical, however, to fully evaluate ICD-11 in light of its current and intended uses. The outcome of this gap and impact analysis should be a clear decision on whether the country will implement ICD-11 MMS.

**Develop an Implementation Plan**

The implementation plan should include a timeline as to when and how ICD-11 will be implemented, including any preliminary or mitigating activities that must be taken beforehand, to ensure a successful deployment. For example, the timeline may depend on whether a country has chosen to implement the ICD-11 MMS; or will first need to allocate resources to define their own linearization. The aforementioned *WHO Implementation or Transition Guide* includes a template timeline.

The task force should also develop specific, measurable goals for the use of ICD-11 consistent with the impact and gap analysis. This plan should be well vetted to ensure sufficient time for regional, state/provincial and local efforts that must take place to align with the national implementation plan. For example, there must be sufficient time for workforce development. In addition, software vendors will need time to plan, develop and test system changes to accommodate ICD-11.

Countries around the globe vary considerably

> In countries that tie healthcare payments, health expenditures, or resource allocation to ICD coded data, a thorough, focused assessment of the impact of moving to ICD-11 must be undertaken

IFHIMA
International Federation of
Health Information Management Associations

in the adoption of EHRs and the level of computerization of their HIS. The automated ICD-11 coding that can be achieved with API integration to an EHR thus requires careful implementation planning. Since a term entered in the patient's record can be transformed into an ICD-11 code via a point-of-care system, data capture expertise from clinicians, informaticians, and HIM professionals is vital in this step. The implementation plan must consider how this might influence the quality and usefulness of the data and design systems consistent with the diverse data uses. Examples of key points to consider when deciding whether to implement point-of-care data capture include:

> Since a term entered in the patient's record can be transformed into an ICD-11 code via a point-of-care system, data capture expertise from clinicians, informaticians, and HIM professionals is vital in this step.

- Do the codes reflect the documentation in the patient's health record? Do they tell the clinical story?

- Have all conditions that were treated been coded?

- What procedures and processes are needed to ensure that accurate and complete codes are entered into the data system?

- What are the uses of the coded data and the implications of inaccurate or imprecise coding?

A final key implementation strategy requirement is ICD-11 education and training to ensure a sufficient number of trained morbidity and mortality coders. This is discussed in more than one of the case studies at the end of this whitepaper.

Reconciling the requirements and needs of the diverse stakeholders and uses of ICD-11 coded data will necessitate careful planning and prioritization as explored above. This reconciliation is critical as decisions must

consider the current and future implementation impact (as relevant to the country) at the national, state/provincial or organizational levels, as well as in the public and private sectors.

## Build ICD-11 Skills and Workforce

Planning for workforce development begins by identifying the ICD-11 competencies and skills needed by the coding professionals. The Canadian case study explores an initial assessment of ICD-11 MMS and the skills needed to transition to ICD-11. Additionally, the WHO/Eastern Mediterranean Region and Japanese case studies explore at a regional and country level, preliminary work assessing the workforce and associated training needs.

HIM professionals, as well as other groups that may be assigning ICD codes, should evaluate their own skills and knowledge in the context of competencies needed for ICD-11. A self-assessment will help an individual identify their knowledge gaps to address needed training objectives and coursework. Existing HIM curricula within educational institutions and new training provided by the WHO or other professional organizations can provide educational resources to help fill the gaps. Toward that aim, Appendix B includes a proposed self-assessment for individuals to evaluate their own skills and knowledge in comparison to anticipated recommended global competencies for ICD-11.

The WHO has a wealth of information available through the ICD-11 information site;[13] a great starting point for a professional association, educational institution, or workplace in seeking ICD-11 training.

Additionally, the WHO is establishing ICD-11 training in the newly created WHO Academy.[14] While the ICD-11 course is not anticipated to launch until mid-2021, the inclusion of this coursework in the WHO Academy is evidence of the importance of the role of ICD-11 in supporting global health and WHO goals. Leading up to the launch, the WHO is establishing course objectives, required competencies, and micro-certification criteria and process. The WHO Education and Implementation Committee (EIC), as discussed in their case study, is a key contributor to this launch.

IFHIMA and its member nations have provided coding and workforce training information and feedback to the WHO throughout 2020. In the upcoming years IFHIMA will closely monitor the needs expressed by our members and continue to provide feedback to the WHO and our constituents.

In an article, *A Preliminary Study on The Current Status of Clinical Coding Education/Training in IFHIMA Countries (2019)*, Dr. Mervat Abdelhak, Associate Professor at University of Pittsburgh and Xiaoya Wang, graduate student at the University of Pittsburgh, provide a preliminary survey of coding education in IFHIMA member nations. The article can be found in the IFHIMA Global News, Issue 14, September 2019.

> IFHIMA and our member nations anticipate that future roles will evolve given the power of ICD-11 and the uses cases explored earlier in this paper.

While historically one of the core competencies and jobs of HIM professionals has been assigning, auditing, managing, and ensuring high quality coded data, IFHIMA and our member nations anticipate that future roles will evolve given the power of ICD-11 and the uses cases explored earlier in this paper. Future roles of the HIM professional may include a focus on data governance and leadership, improving clinical documentation, navigating and using tools that support ICD-11 implementation, translation mapping, upgrading data systems, data analytics, and monitoring/auditing of data derived from artificial intelligence and machine learning. Individuals should consider these future roles when undertaking their self-assessment.

The roles may also be driven in health systems (as defined by the WHO) by the quality and safety use case for ICD-11,[15] which will require consensus on what constitutes a complication or evidence of a quality issue. This would require education and training of clinicians and coders, not only regarding the codes, but also in documenting the event and its cause. Lastly, the adoption of ICD-11 may require a comprehensive review of clinical coder roles and responsibilities. This may require for example, redesign of quality and productivity metrics for clinical coders.

## Unique Challenges and Opportunities for Developing Nations

This section of the white paper addresses common challenges and explores unique opportunities that can arise with the implementation of ICD-11 in developing nations. It should be noted, however, that no two developing nations are the same. Consistent with the IFHIMA Strategic Plan, IFHIMA is using the term developing nations, but organizations use a diverse set of terms to describe nations with a low or moderate economic status.

In developing nations, ICD-10 is the predominant classification system and is used by stakeholders to monitor epidemics and other public health outbreaks, support utilization of resources, evaluate public health programs, and assist with the planning and development of appropriate healthcare services. ICD-10 data also is used by WHO Member States to assess the degree to which a country meets the world healthcare targets such as those in the Sustainable Development Goals (SDGs) also known as Global Goals outlined by the United Nations. The main focus of the SDGs is to promote prosperity while protecting the environment and tackling climate change in all countries (poor, rich, and middle income). Additionally, there is a strong focus on improving equity to meet the needs of women, children, and disadvantaged populations.

In many developing nations, the major challenges anticipated in implementing ICD arose from the limitations in human and financial resources, such as:

- Little or no support for health information systems infrastructure or no Information Communication Technologies (ICT)

- Poor health information systems (generally manual but may be supported with some computerization) along with sub-standard documentation

- Sub-standard or no educational programs for coding work

- Limited recognition of HIM and clinical coding professionals and their work

IFHIMA
International Federation of
Health Information Management Associations

## Coding Workforce in Developing Nations

A health workforce must be adequately equipped with skilled workers to deliver high-quality healthcare to a population. For this reason, the health workforce is identified as one of the six WHO health system building blocks discussed earlier in this whitepaper. Many developing nations have an inadequate number of trained coders. This presents an even greater challenge for developing nations seeking to transition to ICD-11, due the requirement to code to an increased level of detail and anatomic specificity. Fortunately, the structure and components of ICD-11, as discussed earlier in this whitepaper and in the case studies, may ease some of the training challenges.

In some developing nations, the HIM professionals are the clinical coders who are coding morbidity or mortality data. However, their roles and responsibilities may be informal and not recognized or clearly established. These roles should be supported by formal governmental recognition of the profession and understood by all stakeholders.

> In many developing nations, the major challenges anticipated in implementing ICD arose from the limitations in human and financial resources

Lastly, while coding certification exists in many developed nations, it is largely non-existent in developing nations. Healthcare certification is important as it validates advanced knowledge and skills which provides many benefits to patients and their data, as evidenced by the multitude of healthcare certifications.[16] Furthermore, certification ensures a common set of best practices are identified and a common set of ethics are followed. The WHO Academy ICD-11 coursework and its micro-certification may be a key resource in beginning to address these workforce issues.

## ICD-11 Education and Training in Developing Nations

Education and training initiatives for ICD-11 in developing nations will vary as a result of the challenging environment discussed above. In some countries, HIM professionals receive formal education in clinical coding as part of the educational programs. In others, HIM professionals, including clinical coders, may be either taught as part of a short course or solely on the job.

Coding education and training recommendations for developing nations with formal educational programs include:

- Conduct a comprehensive review and revision of the current coding course outline to incorporate the ICD-11 modules

- Develop new courses specifically for ICD-11 taking into consideration the existing education resources already developed or being developed by WHO and the WHO-FIC Education and Implementation Committee (e.g., the ICD-11 electronic training tool and the ICD-11 WHO Academy Course) and the new approaches possible with ICD-11

- Upgrade HIM classrooms by procuring computer systems and upgrading existing infrastructure (e.g., hardware, high-speed internet, and ICD-11 software)

- Leverage coding educational resources available from the regional Collaborating Centers, or WHO regional offices

It should be noted that the above tasks will likely apply to all formal education programs, not just those in developing nations.

Coding education and training recommendations for developing nations without formal educational programs include:

- Develop in-service training and train-the-trainer programs to assist with the introduction and implementation of ICD-11

- Partner with a vendor or educational institution that provides health information/coding educational services or with HIM professionals from IFHIMA member countries

- Leverage resources available from the regional Collaborating Centers or WHO Regional Offices

The WHO Academy ICD-11 coursework should be incorporated into initial ICD-11 training with micro-certification promoted. These two avenues will establish a foundation to work with governments and health systems in securing resources, standardizing job duties, and establishing formal recognition and compensation for the clinical coding jobs.

The 2020-2025 IFHIMA Strategic Plan highlights IFHIMA's commitment to education and training in developing nations.

### Information and Communications Technology (ICT)

ICT will play a critical role in the implementation ICD-11, particularly in developing nations that may lack modern computing ability. The devices, networking components, applications and systems that typically compromise ICT infrastructure are vital components allowing people and organizations to interact in the every-increasing digital world. [17]

Unfortunately, in many developing nations, there are data silos and health information data collection gaps. Multiple standalone HIS with obsolete technologies lack the interoperability of today's EHRs and in some cases, there are limited or no health information exchange standards or information governance in place. In addition, many countries have challenges with consistent, reliable internet access. Without this core technology and reliable high-speed internet services, the web-based version of ICD-11 cannot be leveraged, but the offline version can be used instead.

As previously noted, ICD-11 is specifically engineered for EHRs, although it can also be accessed as a web-based version or a standalone version for a single PC. For countries who do not have local HIS environments, the paper index of ICD-11 is likely to be very cumbersome, quickly out-of-date, and thus, impractical.

Therefore, it is imperative that government authorities mandate and support the integration of ICT into healthcare delivery, especially with the global paradigm shift from paper-based systems to EHRs.

### Governance Structure and Stakeholder Involvement

Support for ICD-11 adoption in developing nations will need to be initiated, championed and funded by the relevant government health and financial ministries and associated stakeholders. Stakeholders will need to consider ICD-11 adoption in light of evolving legal and regulatory frameworks and the transition to digital health. Also, they must be mindful of information governance practices and health information exchange standards that may be maturing in a parallel fashion. The WHO, WHO Collaborating Centers, and WHO Regional Offices may be important resources in this complex journey. In addition, partnerships with telecommunications organizations should be established locally to allow for wide area networks and connectivity. An agile approach will be critical for a successful outcome.

The adoption of ICD-11 will support growth of the HIM and clinical coding professions in developing nations. As countries, regions, and health systems embark on the adoption of ICD-11, they will need to consider their resources, workforce development and capacity building initiatives.

Finally, in developing nations, the ongoing collaboration and discussion between the WHO Regional Offices, WHO Collaborating Centers and MOH will be particularly important. ICD-11 implementation should be seized upon as an opportunity to highlight the vital role clinical data plays in advancing diverse national goals, as well as global health.

> It is imperative that government authorities mandate and support the integration of ICT into healthcare delivery.

## Conclusion: Advancing the ICD-11 Journey

As governments and the global healthcare communities advance their planning and implementation of ICD-11, they should engage HIM professionals early in the process. The multi-stakeholder community that develops the plan, as discussed in this paper, will benefit immensely from the HIM professionals' practical knowledge and core commitment to clinical coding and data management. These are essential ingredients to a successful ICD-11 implementation. Further, the broad data quality expertise, clinical documentation improvement skills, and privacy knowledge held by HIM professionals will be a key asset in advancing the ICD-11 journey.

The case studies included in this whitepaper illustrate critical success factors and early HIM participation in countries around the globe. These case studies also highlight the underlying challenges and importance of education and training, data quality, and workforce development. All of these challenges must be addressed early-on to ensure the anticipated high quality, usable data to advance diverse use cases and global health.

> The multi-stakeholder community that develops the plan, as discussed in this paper, will benefit immensely from the HIM professionals' practical knowledge and core commitment to clinical coding and data management.

As planning begins in earnest in WHO member nations around the world, HIM professionals must keep advancing and expanding their ICD-11 knowledge, demonstrate collaborative leadership and engage with governments and multi-stakeholder collaboratives. HIM professionals must advocate for inclusion in this key initiative from their position of strength and experience.

IFHIMA firmly believes in its vision: "a healthy world enabled by quality health information." ICD-11 planning and implementation will be pivotal for improving health outcomes. The IFHIMA Board and its members hope this whitepaper and case studies inform and inspire those who are embarking on their ICD-11 journey.

IFHIMA
International Federation of
Health Information Management Associations

# Appendix A

Rationale: It is important to know how well ICD is being used for both morbidity and mortality data. The following are key points the task force should explore.

**Mortality data:**

- Is the death certificate recommended by the WHO being used?

- In an organization, who is the individual (s) responsible for completion of the certificate? Is regular training on the completion of the death certificate provided to physicians or other certifiers?

- Which agency is responsible for the collection and reporting of the mortality data?

- Who is responsible for coding of the death certificates? (e.g., clinical coder, physician, statistical officer, other) Is the coding done manually or using automated software (e.g., Iris)?

- Are the certifiers completing the death certificate accurately and comprehensively?

- Have all mortality coders received training on coding the mortality data, in particular selection and coding of the underlying cause of death?

**Morbidity data:**

- Where is morbidity data coded (e.g., hospital, ambulatory care facility, central office)?

- Who does the coding (e.g., HIM, clinical coder, physician, nurse, other)?

- What source documents are used in assigning ICD codes (e.g., just the front sheet of the record, physician's diagnosis plus review of record and results of investigations)?

- Is only the main condition coded or are all diagnoses coded?

- Are there limits to the number of codes that can be used per record?

- Have all morbidity coders received training?

- Have clinicians been taught about the important relationship between clinical documentation and coding?

- Are the clinicians aware of the important role and responsibilities of the clinical coder?

- Is coding done manually or is coding software used?

# Appendix B: ICD-11 Self-Assessment

Rationale: This self-assessment is intended for practicing HIM professionals to evaluate their own skills and knowledge in comparison to the competencies recommended for ICD-11. It can be used as a work plan that assesses what areas one is doing and where there may be some gaps. Also, these competencies and concepts can be included in existing HIM curricula.

Additional skills, to be interwoven throughout these competencies across all skill levels include critical thinking - the ability to work independently, use judgment skills effectively; being innovative, analyze, evaluate and synthesize information.

The assessment should be completed by providing scores from 1 to 3. 1 = does not meet the competency; 2 = meets the competency and 3 = exceeds the competency. After completion, the HIM professional should explore how they may want to fill the gaps for an unfulfilled competency.

| Classification Systems, Vocabularies, Terminologies, Digital Systems:[18] | | |
|---|---|---|
| Level | Competency | Score |
| Foundational | Apply clinical knowledge, rules, and standards to ICD-11 in an electronic environment for morbidity and mortality collections and analytics across multiple healthcare settings. | |
| Foundational | Demonstrate basic understanding, principles, and applications of disease classification systems to include vocabularies, terminologies, and classification systems. | |
| Entry-level | Apply diagnosis/procedure ICD-11 codes to current reimbursement groupings, guidelines/approved standards in the current digital environment using current automated systems. | |
| Entry-level | Evaluate the quality of ICD-11 coding within a digital environment that uses automated coding applications. | |
| Entry-level | Analyze current regulations and guidelines for use with ICD-11. | |
| Intermediate | Lead the evaluation of data quality with focus on ICD-11 coded data and develop appropriate queries to resolve discrepancies | |
| Intermediate | Lead the implementation and evaluation of applications/ systems (encoders, computer assisted coding systems, systems development life cycle, interoperability) for ICD-11 coding, and content standardization | |
| Intermediate | Lead and manage coding quality assessments or audits using appropriate coding and compliance guidelines across all healthcare settings. | |
| Advanced | Manage public health analytics and reporting to the MOH/ WHO and collaborate with healthcare teams on enterprise wide strategic and operational methods. | |
| Intermediate | Lead and manage coding quality assessments or audits using appropriate coding and compliance guidelines across all healthcare settings. | |
| Advanced | Manage public health analytics and reporting to the MOH/ WHO and collaborate with healthcare teams on enterprise wide strategic and operational methods. | |
| Advanced | Develop education and training materials for the ICD-11 system that will address data and content standards as well as software tools for semantic interoperability. | |
| Advanced | Create sustainable apps and electronic information systems that will enhance clinical classification systems, terminologies, and vocabularies. | |

## IFHIMA 2020 ICD-11 Whitepaper Working Group Authors

**Sharon Baker, ACC [UK], CTSS**, is a seasoned health information management professional with over 29 years of experience in clinical coding, decision support and management in healthcare settings in Canada and Wales. She is currently Manager, Classifications and Terminologies – Development with the Canadian Institute for Health Information where she is responsible for the assessment of ICD-11 for use in Canada. Sharon is the Co-Chair of the WHO-FIC Education and Implementation Committee. Contact information: sbaker@cihi.ca

**Megan Cumerlato, BAppSc**, Health Information Management Consultant and current International Classification of Health Interventions (ICHI) Secretariat and Managing Editor for WHO-FIC. Previous Managing Editor for Internal Medicine Topic Advisory Group from 2010 – 2017 for the development of ICD-11. Areas of expertise include classification development, clinical coding educator, coder and auditor nationally and internationally. Contact information: megan.cumerlato@hotmail.com

**Dilhari DeAlmeida, PhD, RHIA** is the current Editor of IFHIMA Global News and is an Associate Professor at the University of Pittsburgh, School of Health and Rehabilitation Sciences in the Department of Health Information Management.

**Vera Dimitropoulos**, with a background in Health Information Management, Vera is currently an honorary research affiliate in the School of Health Sciences, Faculty of Medicine and Health at the University of Sydney. Up to the end of 2019, Vera was the Co-Director at the National Centre for Classification in Health, The University of Sydney. She was elected Co-Chair of the Education and Implementation Committee within the World Health Organization's Family of International Classifications (WHO-FIC) Network in Seoul, Korea in October 2018. Vera has also worked on ICD-11 as part of the International Joint Task Force which ended its mission in Seoul.

**Joon Hong, MPH, HIM**, is a Past President of Korean Health Information Management Association and was an IFHIMA board member. She taught HIM for 30 years at Yonsei Institute for Medical Technology and Yonsei University. She has also been working as a WHO-FIC Education and Implementation Committee member since 2005. Contact information: jh.hong.42@hotmail.com

**Olufunke F. Jayeoba; HND, B.Sc.(HIM), MHIM,** is a HRORBN License Eexamination Assessor and she is also the Deputy Director/ Asst. HOD Health Information Management Department at OAUTHC, Ile-lfe in Nigeria. Contact Information: olufunkejayeoba6@gmail.com

**Carol A. Lewis, MPH, RHIA**, is a Past President of IFHIMA. As a commissioned officer in the United States Public Health Services, Carol was assigned to the Pan American Health Organization and provided HIM consulting services in over 30 countries. She has also been active as a WHO-FIC Education and Implementation Committee observer. Contact information: calewis213@gmail.com

**Deneice Marshall, BS, MS, RHIA, Dip.Ed.** is the current IFHIMA Regional Director for the Americas. Deneice is the Founding President of the Barbados Health Information Management Association (BHIMA) and also the Health Information Management Program Chair/ Coordinator at the Barbados Community College. Contact Information: deneicemarshall@bcc.edu. bb or deneicemarshall@gmail.com; https://www. linkedin.com/in/dlmarshall

**Valerie Watzlaf, PhD, MPH, RHIA,** FAHIMA, President AHIMA (2019), Board Member AHIMA (2018 -2020), member of AHIMA International Advisory Committee and appointed to the National Committee on Vital and Health Statistics (NCVHS) starting October 2020. Valerie is Vice Chair of Education and Associate Professor at the University of Pittsburgh, School of Health and Rehabilitation Sciences in the Department of Health Information Management.

## Endnotes

1. WHO. "ICD-11 Reference Guide." Accessed September 26, 2020. https://icd.who.int/icd11refguide/en/index.html - 1.1.0Part1purposeandmultipleusesofICD|part-1-an-introduction-to-icd11|c1

2. WHO. "WHO | International Classification of Diseases (ICD) Revision." ICD-11 Frequently Asked Questions. World Health Organization. Accessed September 20, 2020. http://www.who.int/classifications/icd/revision/icd11faq/en/

3. "ICD-11 RevisionConferenceReportTokyo.Pdf." Accessed September 20, 2020. https://www.who.int/classifications/network/meeting2016/ICD-11RevisionConferenceReportTokyo.pdf?ua=1

4. Director-General, 72nd World Health Assembly. "Eleventh Revision of the International Classification of Diseases," April 11, 2019. https://dxrevisionwatch.files.wordpress.com/2019/04/a72_29add1-en.pdf

5. WHO. "User Guide." Accessed September 20, 2020. https://icd.who.int/dev11/Help/Get/architecture/en

6. WHO. "ICD-11 Reference Guide." Accessed September 26, 2020. https://icd.who.int/icd11refguide/en/index.html#3.1.0Part3Annexdifferences|part-3-new-in-icd11|c3

7. Sanders, T. B., et al., (2012). The Road to ICD-10-CM/PCS Implementation: Forecasting the transition for providers, payers, and other healthcare organizations. Perspectives in health information management/AHIMA, American Health Information Management Association http://bok.ahima.org/doc?oid=301258#.X8nAkRNKg1I

8. WHO: International Statistical Classification of Diseases and Related Health Problems, ICD https://www.who.int/standards/classifications/classification-of-diseases.

9. "ICD-11 Implementation or Transition Guide_v105.Pdf." Accessed September 26, 2020. https://icd.who.int/docs/ICD-11%20Implementation%20or%20Transition%20Guide_v105.pdf

10. World Health Organization (WHO). (2010a). Monitoring the building blocks of health systems: A handbook of indicators and their measurement strategies. Geneva, Switzerland: WHO. http://www.who.int/healthinfo/systems/WHO_MBHSS_2010_full_web.pdf

11. WHO. "ICD-11 Maintenance Platform." Accessed November 25, 2020. https://icd.who.int/dev11/f/en

12. WHO-FIC, Information Sheet, September 2012. "International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10)" https://www.cdc.gov/nchs/data/icd/ICDInformationSheet.pdf

13. World Health Organization (WHO). "ICD-11." ICD-11. Accessed September 27, 2020. https://icd.who.int/en

14. WHO. "WHO Academy." Accessed September 27, 2020. https://www.who.int/about/who-academy

15. WHO. "ICD-11 Reference Guide." Accessed September 27, 2020. https://icd.who.int/icd11refguide/en/index.html#2.25.3MorbidityforQualandPS|morbidity-for-quality-and-patient-safety|c2-25-3

16. AHIMA Certifications Overview. https://www.ahima.org/certification-careers/certifications-overview/

    American Association of Nurses. Certification Benefits Patients, Employers and Nurses https://www.aacn.org/certification/value-of-certification-resource-center/nurse-certification-benefits-patients-employers-and-nurses

    Health Information Management Certification http://www.himconnect.ca/meet-him/faqs/him-certification - :~:text=The Canadian Health Information Management, excellence in health information management

17. TechTarget. Definition. Networking (computer) https://searchnetworking.techtarget.com/definition/networking

18. Global Academic Curricula Competencies for Health Information Professionals by the Global Health Workforce Council AHIMA, AHIMA Foundation, IFHIMA, June 30,2015
    NEED URL HERE

## References

2020-2025 IFHIMA Strategic Plan, On 28 September 2020, the International Federation of Health Information Management Associations (IFHIMA) Board of Directors released its 2020-2025 Strategic Plan. https://ifhima.org/2020-2025-strategic-plan/

Privacy of Health Information, an IFHIMA Global Perspective, Copyright IFHIMA November 2019, https://ifhima.org/whitepapers/

## Disclaimer

This whitepaper reflects the views of the International Federation of Health Information Management Associations (IFHIMA), and not necessarily its sponsors, partners, affiliates or members. This whitepaper offers no legal nor consulting advice. IFHIMA is not responsible for actions taken as a result of reading or using the whitepaper. IFHIMA is not liable for the contents of external links. Responsibility for external links belongs to their operators.

# Sponsors

For the first time ever, IFHIMA invited outside organizations to help us offset the cost of producing this whitepaper. We thank these sponsors for their financial contribution and for supporting our vision for "a healthy world enabled by quality health information." We are delighted that they've joined the IFHIMA effort to advance high quality data and ICD-11 adoption.

Please visit their websites or social media platforms to learn more about their commitment to quality health information and global health.

## Platinum



ASHO, as a leading company in healthcare coding, currently manages more than 85 projects throughout Spain and codifies around 600,000 registrations per year. With a 47% market share, the company specializes in offering value-added services in hospital information systems, which facilitate the management and work of clinical professionals. Since its inception 26 years ago, it has encoded more than 8 million registrations, concentrating 2.5 million in the last five years. This year, ASHO made its international debut, winning its first competition outside Spain, opening up to the international market in Europe. In the future, the company will increase its expansion.

**asho.net**

## Gold

3M Health Information Systems empowers providers, payers and government agencies to anticipate and navigate the evolving health care landscape. From computer-assisted coding to clinical documentation integrity and performance monitoring, 3M is committed to eliminating revenue cycle waste, creating more time to care and is leading the shift from volume to value-based care. We are closing the loop between clinical care and revenue integrity, providing clinicians with real-time guidance and accurate documentation.

**www.3M.com/his**

The Coding Company, an Australia based global company, employs highly skilled and experienced Clinical Coding, HIM and senior advisory staff who serve the healthcare sector. We have the depth of resources and subject matter experts in audit, costing and revenue cycle management, information technology and infrastructure planning to provide our clients with a comprehensive service in HIM and Clinical Coding. Remote and onsite clinical coding is one of our many strengths.

The Coding Company has developed close ties with the industry we have served over many years and we believe our reputation as a good employer and excellent service provider uniquely qualifies us.

**thecodingcompany.com.au**

Transforming clinical data into actionable information requires standardization of clinical terms. Kathy Giannangelo Consulting, LLC, specializes in clinical data transformation through terminology feasibility assessment, adoption methodology appraisal, and implementation support. Consulting services include evaluation of terminologies based on desired use case, requirements analysis and documentation, concept mapping to standard terminologies (e.g., SNOMED CT, ICD-10, ICD-11, CPT), legacy data conversion, and data standard migration strategies. Additional services offered are clinical terminologies and classifications education and training.

**www.linkedin.com/in/KathyGiannangelo**

## Silver

**CHiA**
AHiMA Affiliate
California Health
Information Association

California Health Information Association is dedicated to the development of its heath information professionals. A state affiliate of AHIMA, its vision is to ensure improved health through trusted information.

**www.californiahia.org/**

الجمعية السعودية لإدارة المعلومات الصحية

Saudi Health Information Management Association

Saudi Health Information Management Association is a non-profit organization aiming to promote the field of Health Information Management in Saudi Arabia and the Arab region. SHIMA's objective is to empower HIM professionals through advocacy, communication, education and research.

**www.shima.org.sa/**

HERA - INDIA

Health Records Association of India (HERA-I), a National Association representing members all over India. Promotes the health information management values through conferences, workshops, and by participation in National initiatives.

**www.herai.in**

**SEDOM** Sociedad Española de Documentación Médica

The Spanish Society for Medical Documentation (SEDOM), founded 1985, is a scientific society that groups medical doctors responsible of Health Information Management and Clinical Documentation.

**www.sedom.es/**

IFHIMA
International Federation of
Health Information Management Associations

# Case Studies In ICD-11 Planning and Implementation

**IFHIMA**

International Federation of
Health Information Management Associations

**About IFHIMA**

The International Federation of Health Information Management Associations (IFHIMA) is a non-governmental organization (NGO) in official relations with the World Health Organization (WHO). The Federation acts as the global voice of the health information management profession, supporting the importance of education and training, high quality health data, and privacy of health information. IFHIMA is committed to the advancement of health information management practices and the development of its members for the purpose of improving health data and health outcomes.

- Would you like to keep informed on IFHIMA? Sign up here.

- Did someone kindly share this whitepaper with you? You can get your own digital copy here as a free download.

- Yes! You may share – reprint with permission when you use this citation:

  Source: IFHIMA Fosters Planning for ICD-11 Adoption with Global Case Studies, ©Copyright International Federation of Health Information Management (IFHIMA), January 2021. Reprint with permission.

# Clinical Coders as Researchers in a Field Trial Testing ICD-11 for Mortality and Morbidity Statistics Coding: A Case Study from Canada

Cathy Eastwood
RN, PhD

## Introduction

Health information management clinical coders are extremely valuable as research team members. Their expertise in medical terminology, classification of diseases, and coding skills, were required for this Canadian study. During the development of ICD-11 for Mortality and Morbidity Statistics (ICD-11 MMS), the World Health Organization (WHO) called for systematic field trials for testing the beta version of the ICD-11 browser and coding tools. Researchers were encouraged to examine the fitness of ICD-11 for multiple purposes around the world and to test compatibility between ICD-10 and ICD-11. While participating in this research opportunity, clinical coders spent months coding hospital records then gave detailed feedback to WHO committees before ICD-11 was adopted by the World Health Assembly on 28 May 2019[1].

The University of Calgary is a WHO Collaborating Centre for Classifications, Terminologies, and Standards, with experience in research related to validating and enhancing disease classification. As such, in 2015 a research team led an ambitious multi-stage field trial that was awarded funding from the Canadian Institute for Health Research. The team's goal was to proactively contribute to ICD-11 development for classifying conditions related to disease states and quality and safety events, from being active participants on the WHO ICD-11 committees (Morbidity Reference Group, and Quality and Safety Topic Advisory Group). Hence, the field trial purpose was to demonstrate ICD-11 coding features for the Canadian government and related agencies for ICD-11 adoption decision-making, and to generate high quality data for discussion at the World Health Assembly before adoption. This approach is a good example of the need for thorough, multi-disciplinary planning, as explored in the "ICD-11 Adoption and Implementation Strategies" section of this whitepaper.

## Problem Statement/Background

Given the new codes and structural changes to the ICD-11 classification system, there was little information on training requirements for clinical coders, how ICD-11 coding tools would perform, or how coding would be conducted on full patient records. Hence, a real-world field trial was needed. To conduct such a field trial, a three-way collaboration between the University of Calgary, Canadian Institute for Health Information (CIHI), and WHO members was established to develop training materials and resolve coding and tooling issues that arose during the study.

The study was conducted between October 2017 and June 2018. Six clinical coders were hired and trained. They brought with them expertise in coding, coded data analysis, or quality assurance. The training materials that were developed and shared with the WHO committees can be found at Coding with ICD-11 U Calgary.[2] As research team members, the clinical coders participated in monthly meetings, and coding time in addition to their regular health information management jobs. Training consisted of 20 hours in a classroom to learn ICD-11 principles. Then, practice coding concepts and short scenarios were provided as homework. Answer codes were reviewed in the group setting. After inter-rater reliability for coding the main condition reached a satisfactory level (over 80 percent agreement), coding was completed on 3074 full (previously coded using ICD-10-CA) randomly selected adult hospital discharges (obstetrics/births excluded). This sample size was calculated to be sufficient for comparing codes for a list of common chronic conditions and hospital acquired harms.

Throughout the coding phase, the team met monthly to discuss challenges – missing codes, duplicate codes, and how to code complex concepts like hospital-acquired injuries or infections. At the onset of the study, a beta version of ICD-11 was available but was still changing during the early study phase. Coding advice was provided by a consultant engaged by the WHO and coding experts from the Canadian Institute for Health Information. Where the coders encountered new situations or found gaps in the ICD-11 browser, the WHO consultant forwarded the comments for review to WHO committees. Great discussion took place on how to select ICD-11 codes and how to use the new three-part model for coding hospital harms. As a result, a coding decision tree was developed by the coding team and included in the ICD-11 Reference Guide (Section 2.25.5.2, Figure 1)[3].

## Discussion and Recommendations

Throughout the training and coding process, the six clinical coders commented on the experience of learning ICD-11 coding. A questionnaire, interviews, and a quiz of the coding team enabled opinions and knowledge to be documented. In brief, coders found the group discussions most helpful and the slide content least helpful. They enjoyed practice coding and comparing code choices with their teammates. It took a lot of perseverance to complete over 3000 records, but intense satisfaction and celebration came after coding was complete at three hospitals.

As the study lead, the greatest reward from this collaborative project was watching clinical coders gain proficiency with using ICD-11 and seeing the intense pride that came from making substantial contributions to the ICD-11 codes, browser content, and coding tool functions. In two instances, the clinical coders were invited to share their unique experience with members of WHO Morbidity Reference Group and at the WHO-FIC Annual Meeting in Banff, Canada, 2019. The clinical coders provided case examples of gaps in the browser and their ease or difficulty using the coding tool. They reported that the greatest improvement over ICD-10 was the ability to tell the full patient story by coding specific myocardial arteries or by linking together multiple injuries using cluster codes in ICD-11. From the training materials, here is an example of a scenario coded using ICD-11.

*The patient presented to the emergency department with several days' history of fever, chills and small-volume hemoptysis. She had progressively worsening hypoxemia resulting in hypoxic respiratory failure requiring intubation and transfer to the intensive care unit. She had a bronchoscopy which did not reveal any evidence of alveolar hemorrhage. A BAL sample ultimately came back positive for H1N1. She received a course of Tamiflu for this. With these interventions, her respiratory status improved, and she was ultimately extubated and transferred to the floor.*

**Main condition:**        H1N1 Influenza

**Other conditions:**       Hypoxic Respiratory Failure

| Expected Code assignment | |
|---|---|
| **Main Condition** | **ICD-11 Live version April 03 2018** |
| Influenza due to identified zoonotic or pandemic influenza virus & Main resource condition & Present on admission | 1E31&XY7B&XY6M |
| **Other Conditions** | |
| Respiratory failure, unspecified, Type I & Developed after admission | CB41.20&XY69 |

## Conclusion

Six clinical coders significantly contributed to a large real-world field trial that tested the Beta Version of ICD-11 classification system and coding tools. Through involvement in this study, these information management professionals:

• Enhanced the WHO's ICD-11 online browser, reference guide, and educational materials

• Were the first to code full length medical-surgical hospital records and to provide feedback directly to WHO committee members

• Gained rare and valuable research experience

• Received opportunities to advance to new positions using their ICD-11 expertise

## About the author

**Cathy Eastwood**, RN, PhD, is an Adjunct Assistant Professor in the department of Community Health Sciences and Operations Manager of the Centre for Health informatics. Dr. Eastwood's research focuses in part on health data quality and precision health projects. Dr. Eastwood sits on various WHO ICD-11 working groups to advance coded data quality. For more information, see Calgary Centre for Health Informatics.

### References

1. *Eleventh revision of the International Classification of Diseases, SEVENTY-SECOND WORLD HEALTH ASSEMBLY, WHA72.15, Agenda item 12.7, 28 May 2019*
   *https://apps.who.int/gb/ebwha/pdf_files/WHA72/A72_R15-en.pdf?ua=1*

2. *Cathy A. Eastwood, Danielle A. Southern, Chelsea Doktorchik, Shahreen Khair, Denise Cullen, Alicia Boxill, Malgorzata Maciszewski, Lucia Otero Varela, William A. Ghali, Lori Moskal, and Hude Quan. n.d. "Foundational Concepts of ICD-11 with Case Scenarios and Coding Example Worksheets to Supplement Learning and Implementation." Retrieved September 27, 2020 https://cumming.ucalgary.ca/node/409627*

3. *ICD-11 Reference Guide-Figure 1 Q&S Algorithm*
   *https://icd.who.int/icd11refguide/en/index.html#2.25.5CodesetPSQ%7Ccausation-in-the-context-of-quality-and-safety%7Cc2-25-5-1*

# Case Study: WHO/Eastern Mediterranean Region (WHO/EMR) ICD-11 Workforce

Zahyiah Ahmad Al Amry

Dr. Azza Mohamed Badr

## Introduction

Efforts have been ongoing in developing ICD-11 and its readiness around the world since the release in May 2019; this case study will share the journey so far for some of the countries in the World Health Organization/Eastern Mediterranean Region (WHO/EMR) as they collaborate with the WHO/EMR Regional Office (WHO/EMRO).

The Regional Office (WHO/EMRO) provided reinforcement of the training and technical support through regional and national workshops. Additionally, they provided follow up on the piloting and implementation of the new classification. Countries in the WHO/EMR have already started piloting and implementing ICD-11 for Mortality and Morbidity Statistics (ICD-11 MMS) for either mortality or morbidity reporting or both, as an initial phase. As the EMR countries further engage in the implementation of ICD-11, they are contributing to the process of assessing the comprehensiveness of the classification. Moreover, member states in the WHO/EMR are expected to share their feedback to WHO on the piloting progress in addition to the appropriateness of the translation and proper functioning of the search engine of the Arabic translation of ICD-11. The full Arabic translation has been released on the WHO public domain in October 2020.

## Background

As was the past case of ICD-10 implementation, a number of papers and studies shared the same impression of the challenges in adapting and implementing the ICD-10 classification. It took several years in some countries to be ready for implementation. With this in mind, the WHO/EMR took the opportunity to be among the pioneers of ICD-11 in both implementation and resources/capacity building, with select countries volunteering to participate in a pilot to enable the continuous preparation for ICD-11. It should be noted that the examples in this case study reflect using the English version of ICD-11 as the Arabic translation was not yet available.

Until 2020, only 17 of the 23 EMR countries had used ICD-10 codes to report mortality statistics to WHO.

The World Health Organization has focused on the ICD-11 release to have a better way of capturing data and reporting mortalities and morbidities while leveraging the offered tools and their ability to integrate with health information systems (HIS); all of these aspects are meant to improve quality of health and reduce cost (WHO, 2019)[1]. Therefore, this release would have better capabilities supporting scientific research and medical advancements globally and locally within the healthcare systems.

One of the benefits of ICD-11 is its capacity to better code and therefore measure antimicrobial resistance and patient safety. In that context, the Kingdom of Saudi Arabia (KSA), also a member state in the WHO/EMR, hosted the Fourth Global Ministerial Summit on Patient Safety in March 2019, in Jeddah, KSA. The Summit aimed to continue the Patient Safety Summit series which started back in 2016 which has been hosted by the United Kingdom, the Federal Republic of Germany, and Japan, with the endorsement of the WHO. These events brought together patient safety experts, decision-makers, ministers, and people interested in patient safety and achieving universal health coverage (UHC) in all countries.[2]

Jeddah Declaration on Patient Safety[3] is to maintain the momentum of the global patient safety movement, especially within the low and middle-income countries (LMICs), The Jeddah Declaration endorses the previously agreed on objectives from the Tokyo Declaration on Patient Safety presented during the 3rd Global Ministerial Summit on Patient Safety in 2018, Tokyo, Japan. The Jeddah Declaration covered an initiative focused on improving the understanding and the magnitude of Adverse Events (AEs) in healthcare, as well as the promotion of better use and adoption of ICD-11. Hence, the recommendation came to establish the International Classification of Adverse Events (ICAE) under the ICD-11 umbrella which would help with standardization of capturing and recording taxonomy of adverse events in collaboration with the Saudi Patient Safety Center (SPSC).

## Discussion and Recommendations

WHO/EMRO in collaboration with WHO/HQ (Headquarters) intensified its technical support to countries in the region with the intention of expediting the implementation of ICD-11 due to its added value in monitoring and reporting of morbidity and mortality as discussed in the "Unique Challenges and Opportunities for Developing Nations" section of this whitepaper. The three levels of the organization, namely the EMR Regional office, WHO/HQ and the WHO country offices conducted a series of national workshops, which started in the second half of 2018.

The objective of these workshops was targeting the key stakeholders within each country to gain their acknowledgment for requirements for workforce training and development including, and not limited to, the HIS national focal, MOH, HIM professionals, coders and statisticians on the newly launched ICD-11 to facilitate and accelerate its implementation in the EMR. It was noted that there was limited involvement of the HIM professionals in these regions.

It is hoped that this case study will bring additional recognition for the value of HIM professionals in the planning and rollout of the ICD-11 implementation, as elaborated in sections of the whitepaper. Many challenges face HIM professionals globally, yet it seems more challenging in the EMR countries where the HIM profession is undervalued and understaffed.

## WHO/EMR Milestones & Feedback

As we highlight milestones and successful implementations in a number of countries within the EMR, including Egypt, Iran, Iraq, Jordan, Kingdom of Saudi Arabia, Kuwait, Tunisia and UNRWA, different workshops were delivered for country-wide or region-specific implementation. The process of feedback was kept within the discretion of each country at this phase including the level of involvement of the HIM professionals.

### Egypt:

WHO/EMRO started the journey of ICD-11 implementation in Egypt when they conducted a national capacity-building workshop for MOH staff and for the WHO/Egypt country office staff in June 2019 in Sharm El Sheikh, Egypt. The MOH Egypt decided to adopt ICD-11 in its newly developed HIS for the National Health Insurance System for morbidity coding. By November 2019, Egypt had started implementing ICD-11 in Port Said Province.

Next steps for Egypt MOH, is their plan to include ICD-11 for causes of death in the electronic deaths notification/registration system after training physicians working in the health offices on ICD-11 mortality coding.

### Iran:

The WHO/EMRO conducted an ICD-11 workforce development workshop in Tehran, Iran for MOH staff. The MOH Iran, had decided to pilot ICD-11 in their HIS for two 1,000 bed MOH hospitals in Tehran for morbidity reporting and coding. By June 2020, MOH Iran had piloted ICD-11 for morbidity for 16 months.

Additionally, the piloting hospitals were able to identify diagnoses that were either missing or needed further specificity. These were then submitted to the WHO/EMRO, and in collaboration with the Iran MOH representatives communicated to WHO Geneva in order to get the codes updated and/or added to the released ICD-11.

### Iraq:

IRAQ MOH is also piloting ICD-11 in their national death notification system based on advice and technical support from WHO/EMRO. More extensive capacity-building for Iraq MOH HIS staff and physicians was planned for 2020 when the COVID-19 pandemic took place. Efforts will resume when feasible.

### Jordan:

WHO/EMRO conducted two ICD-11 workforce development workshops in Amman, Jordan for all WHO/EMR countries. MOH Jordan decided to pilot ICD-11 in their HIS of two MOH hospitals for morbidity reporting and coding. MOH Jordan also developed an electronic death notification platform in the ICD-11 environment to be used for mortality notification and coding nationwide. The results of this pilot have not yet been submitted to WHO/EMRO.

### Kingdom of Saudi Arabia:

The introduction of ICD-11 for mortality reporting aims to enhance the current process, replacing the use of ICD-10 and allowing the mortality reporting to be associated with more than one condition as cause of death. Moreover, this enhancement will be inclusive to interface multi-governmental systems allowing data dependability and integration. For example, when an individual is deceased their data will be connected to all relevant governmental entities, such as banking and insurance. This is key factor for reducing identity theft.

The MOH Saudi Arabia had considered implementing the ICD-11 mortality coding to be nation-wide by late 2020. As of this writing, the current COVID-19 pandemic restrictions have impacted the plan for training and conducting ICD-11 capacity-building workshops.

### Kuwait:

WHO/EMRO conducted an ICD-11 capacity-building workshop in Kuwait City, Kuwait, for all WHO/EMR countries. MOH Kuwait had decided to pilot ICD-11 in their HIS of one MOH hospital and one PHC center for morbidity reporting and coding. They also developed an electronic death notification platform in ICD-11 environment to be used for mortality notification and coding nationwide. The results of this pilot have not yet been submitted to WHO/EMRO.

### Tunisia:

WHO/EMRO conducted an ICD-11 workforce development workshop in Tunisia in 2019 for the staff of the National Institute of Public Health. The WHO/EMRO assisted the National

Institute of Public Health in developing an electronic deaths notification platform, in the ICD-11 environment. The new electronic deaths notification platform follows the format of the WHO 2016 International Death Certificate.

By June 2020, the National Institute of Public Health had piloted the electronic death notification platform in two hospitals for 15 months.

**UNRWA (United Nations Relief and Works Agency):**

For the Department of Health UNRWA, the WHO/EMRO conducted two ICD-11 workforce development workshops in Amman Jordan (Headquarter), for their physicians in the five UNRWA fields: Jordan, Syria, Lebanon, Gaza and West Bank during July 2019. As a result, the UNRWA Health Department made the decision to update their HIS to enable migration to ICD-11. During the first quarter of 2020, the UNRWA Health Department had concluded the updating of the primary healthcare (PHC) HIS. And the WHO/EMRO conducted five one-day capacity-building workshops in ICD-11 in morbidity coding for all UNRWA/Jordan field PHC physicians.

Currently, the UNRWA Health Department has begun using ICD-11 in their HIS in all of its PHC centers. The UNRWA health officials are now equipped to conduct their own training for ICD-11.

## Conclusion

The initial wave of capacity-building workshops within the EMR countries is a successful milestone for the WHO/EMRO, WHO/HQ and the participating countries; the WHO/EMRO will continue to receive feedback and provide support to those countries to further engage in the rollout of ICD-11. However, it was observed that the role and level of engagement of the HIM professionals in those countries is limited and not clearly identified, leaving a gap of HIM knowledge and expertise that should be considered and can contribute to the success for capacity-building workshops and implementations.

This may be a factor due to the limited number of experienced and identified HIM professionals in those countries, as discussed earlier in details in this IFHIMA whitepaper under the "Unique Challenges for Developing Nations." There is an urgency and need to acknowledge the HIM professionals in these countries as they are indeed needed to participate in a successful rollout of the ICD-11 as set by the WHO.

The WHO/EMRO are aiming for additional capacity-building workshops to be carried out in 2021 (after COVID-19 restrictions are lifted). The Ministries of Health in the EMR must acknowledge the need to involve more competent HIM professionals in the workshops to plan, manage and execute the ICD-11 implementation. Their technical and professional skills will permit them to engage with the countries attending the workshops and analyze the feedback from the EMR countries to assist them in planning next steps.

HIM professionals in EMR should leverage the HIM expertise from local or global HIM associations, and other countries to obtain lessons learned and further guidance and support to achieve the desired successful outcomes.

## About the Authors

**Zahyiah Ahmad AlAmry**, BSc HIM, MBA, HIM Director at Johns Hopkins Aramco Healthcare Company, Secretary General for Saudi Health Information Management Association (SHIMA) (2019-2022). LinkedIn: https://www.linkedin.com/in/zahyiah-alamry-0532843b/ Twitter: https://twitter.com/zahyiah

**Dr Azza Mohamed Badr**, BSC, MSC, DPH, PhD, Technical Officer, Vital Statistics and Country Support, Health Information Systems, Information, Evidence and Research Department within the Eastern Mediterranean Regional Office – EMRO at the World Health Organization – WHO. LinkedIn: https://www.linkedin.com/in/dr-azza-badr-31589216/

### References

1.  WHO, "ICD11 Implementation or Transition Guide", p2-3, Online, 2019, https://icd.who.int/docs/ICD-11 Implementation or Transition Guide_v105.pdf

2.  SPSC, "4th Global Ministerial Patient Safety Summit 2019", p1, Online, 2019, https://www.spsc.gov.sa/English/Summit/Pages/About-the-Summit.aspx

3.  SPSC, "The Jeddah Declaration on Patient Safety", p3, Online, 2019, https://www.spsc.gov.sa/English/Summit/Documents/%D8%A7%D9%84%D9%85%D9%88%D9%82%D8%B9.pdf

# Case Study: Planning for ICD-11 in Japan

Yukiko Yokobori

## Introduction

Since the revision work of ICD-11 was started in Japan, the government, the Japan Hospital Association (JHA), the Japan Society of Health Information Management (JHIM), and related academic societies have been preparing for the ICD-11 implementation. The main preparation points for the ICD-11 implementation, using ICD-11 MMS throughout this work are:

- Translation of ICD-11 from English to Japanese

- Education for new classification including International Classification for Functioning Disability and Health (ICF) and the International Classification for Health Intervention (ICHI)

- Consideration of ICD-11 and its uses for medical service fee calculations and payments which will greatly impact medical service fee systems

The government and related institutions are working to translate ICD-11 into Japanese, which is a very difficult task. Meanwhile, HIM professionals are required to respond to ICD-11 promptly since ICD-10 is used for the medical expenses system in Japan. Therefore, the JHIM identified the issues for the ICD-11 implementation in Japan, examined potential solutions, and conducted a study in 2019 for the purpose of defining and understanding how to ensure a smooth dissemination and enlightenment.[1]

## Problem Statement/Background

A total of 32 veteran HIM professionals and doctors (who are also qualified as HIM professionals) participated in the above study. The objective of this study was to verify the difference and the equivalence of ICD-10 and ICD-11, and create additional educational materials based on the WHO ICD-11 Reference Guide for training educators and HIM professionals. The JHIM started to create additional educational materials in 2019.

The first workshop which used output from the 2019 study was held using the educational materials in Tokyo in May 2019 when 471 members of the JHIM participated. The JHIM also conducted a questionnaire after the workshop which reflected that 87.9 percent of HIM professionals who participated in the workshop were hospital workers.

## Discussion and Recommendations

The workshop participants shared that the most difficult parts of ICD-11 to understand and correctly apply codes were:

1. Section X Extension codes (the most difficult)

2. Section V Supplementary Section for Functioning

3. Chapter 26 Traditional Medicine. Neoplasms

4. Chapter 2 Mental, behavioral or neurodevelopmental disorders

5. Chapter 6 Diseases of the nervous system

6. Chapter 8 Diseases of the skin

7. Chapter 14 Diseases of the musculoskeletal system or connective tissue

8. Chapter 15 Injury, poisoning or certain other consequences of external causes

Based on the results of the questionnaire, educational materials need to be revised so that the coders' understanding could be deepened. In addition, the educational materials and workshop in the first year were mainly focused on the differences between ICD-10 and ICD-11 and could not anticipate specific future problems. Thus, it is necessary to develop more practical educational materials using real-world discharge summaries to identify future problems that might occur when using ICD-11. It is essential to educate those who can provide guidance in each region within Japan and to provide training programs on the web. While the need for web-based training is critical during the COVID-19 pandemic, it will also be important in the future.

There is a major issue with the lack of a renewal or continuing education system for HIM professionals in Japan. Some HIM professionals have not improved their skills after meeting qualifications. The need to assess and upgrade skills is discussed in the "Build ICD-11 Skills and Workforce under the "ICD-11 Adoption and Implementation Strategies" section of the body of this whitepaper.

With the implementation of ICD-11, digitalization will be progressed, and the type and amount of information handled by HIM professionals will be increasing in the future. Because the accuracy of the information is required, HIM professionals need extensive expertise to handle a large amount of the information. Therefore, training programs are needed to help HIM professionals continually improve their skills.

International Classification of Functioning and Disability in Health (ICF) and International Classification of Health Interventions (ICHI) are not included in the HIM education in Japan today. It is necessary to promote the research and development of teaching materials so that ICD-11, ICF, and ICHI can be utilized to provide more information. The JHIM is currently considering ICF and ICHI education in lifelong education for HIM professionals, with educational activities scheduled to start in 2021.

IFHIMA
International Federation of
Health Information Management Associations

Lastly, the impact of changing from ICD-10 to ICD-11 to the Japan medical service fee calculations and payment system must be thoroughly explored. Based upon the exploration, changes or modifications to systems must then be designed and executed. Only after this crucial step can ICD-11 implementation proceed. Considerations include:

- Discussion and analysis of the impact to clinical and financial systems and documents

- Approval from the related and impacted organizations

- Funding and time allocation to change the systems and documents

- Education and training of the workforce at each medical institution

These high-level tasks and many associated details are essential to ensuring the usefulness and reliability of ICD-11.

## Conclusion

It is important to motivate HIM professionals in Japan, as well as globally, to improve their skills, to recognize the importance of this qualification to the world, and to provide a mechanism for internationally assessing the skills of HIM professionals. These steps can ensure global success. International certification, in cooperation with international organizations such as the WHO (as explored in the body of this whitepaper) will play a role in advancing ICD-11 adoption and the HIM profession.

## About the author

**Ms. Yukiko Yokobori** is the special advisor of the Japan Society of Health Information Management (JHIM). Yukiko has been participating in the activities of the WHO-FIC Network since 2003. She served as the Co-Chair of the WHO-FIC Education and Implementation Committee (EIC) from 2014 to 2018. In the field of ICD implementation, she assisted in the establishment of the WHO-FIC Asia-Pacific Network in 2006 and has been serving as the Network's secretariat. From 2010 to 2016, she served as the Regional Director, South East Asia of IFHIMA. Within the WHO-FIC Collaborating Centre in Japan, she has overseen the training of ICD and ICF in Japan since 2011. Contact information: yokobori@jha-e.com

### References

1. *Hiroyuki Suenaga, M.D., Representative of the Research on Statistics and Information Policy, Health and Labour Sciences Research Grants, the Ministry of Health, Labour and Welfare, Japan. [Extraction and Solution of Issues Regarding the Implementation of ICD-11 Coding in Japan and Information Analysis on Morbidity Statistics in Developed Countries] 2020. https://www.mhlw.go.jp/seisakunitsuite/bunya/hokabunya/kenkyujigyou/hojokin-koubo-2019/gaiyo/01-02.html*

# The Experience of Collaborative Translation of ICD-11 Beta Draft into Spanish: A Case Study

Gemma Gelabert Colomé MD.

Artur Conesa González MD PhD.

## Introduction

The World Health Organization-Family of International Classifications (WHO-FIC) Network is developing the ICD-11 in response to align the demands of the classification with the latest scientific evidence and to meet user requirements. Among the different activities related to these developments, they offer a possibility of participation in field trials. It is in this context that in 2015, the Collaborating Centers for the WHO-FIC in the Americas and in Barcelona (PAHO/WHO-FIC Network) started working with the Pan American Health Organization (PAHO) on the ICD-11 revision.

## Problem Statement/Background

The Collaborating Centers (CCs) for the WHO-FIC in Venezuela (CEVECE), Mexico (CEMECE), and Argentina (CACE), the National Reference Centers in Cuba (CECUCE), Chile and Colombia, and the Collaborating Center in Barcelona (CC-BCN) (under designation) have formed the PAHO/WHO-FIC Network and they are also part of the RELACSIS (Latin American and Caribbean Network to Strengthen Health Information Systems).

Since 2015, the Network has started a collaborative translation of the ICD-11 beta draft into Spanish in order to better contribute to the ICD revision and participate in the field testing. This work was coordinated by the Health Analysis & Information Unit at the Pan American Health Organization (PAHO/WHO). The global population potentially impacted by this translation will be of almost 600 million people.

As the translation was designed and executed, the CCs were mindful of the goals of ICD-11 as discussed throughout this whitepaper.

### Plan the work and work the plan

This activity has brought an overload of work for the CCs, so the solid commitment from their members with the improvement of health statistics was the key.

From February 2015, the PAHO/WHO-FIC Network has been holding virtual meetings every two weeks in order to:

- Follow up on the progress of the collaborative translation

- Exchange experiences

- Reach a common understanding of the process

- Discuss technical documents and be updated with the global advances and plan

The CCs agreed on distributing the chapters according to their interest and expertise. The initial work was focused on the translation of the priority chapters for the first phase of the field trials (neoplasms; diseases of the blood; diseases of the ear; diseases of the visual, circulatory, digestive and genitourinary systems; pregnancy & childbirth, and injury and poisoning). Responsibility for each chapter, deadlines for translation and revisions, were established.

At first, general translators responsible for each chapter were assigned by the Collaborating Centers. Later, experts were assigned for the necessary revision of the content translated. Next, reference translators were assigned for the final approval.

During the work plan development, it was necessary to provide virtual training on how to access the platform. The WHO and CC-BCN played an important role in this activity and then CACE and CECUCE were able to train new participants and develop tutorials to help them.

Furthermore, CACE and CECUCE developed some practical guidelines on how to access the platform that were important for new volunteers.

Since the translation started, the translators noticed that some important terms should be standardized among them. A document, Translation's Agreements, fed by translators, was circulated to have the input of the Network.

**Some examples of these agreements are:**

- To translate "Drugs" it was decided to use as the preferred term the word "medicamentos" instead of "drogas", as is referred in ICD-10 volume 3, or to translate "nodal" to "ganglionar" instead of "nodular", or "vacunación" instead of "inmunización", including the second ones as synonyms.

- Regarding the translation of the acronyms, in spite of the common use of some of them in English in Spanish-speaking countries, it was agreed to translate all of them.

Furthermore, it has been included in the "Agreements" specific information addressed to the team, such as:

1. Objectives of the document: standardize the translation; decrease the variability between the different Centers, guide translators and proofreaders.

2. What should be translated? At this stage, the titles, inclusions and exclusions of the priority chapters for the pilot tests will be translated (2; 3; 5; 10; 11; 12; 14; 17; 18; 22). Note: other inclusion terms not considered in the ICD-10 can be added.

3. Guidance for translation was to keep the terms that are already in the ICD-10.

## Discussions and Recommendations

Between April 2015 and August 2016, a total of 109,497 entities in ICD-11 beta draft were translated into Spanish, making it possible to participate in a 2016 field test. Once accomplished, the goal was to have 60-70 percent of entities translated in each chapter.

Other key elements were also translated, and technical materials were developed such as platform (CEMECE), a Reference Guide and the ICD-11 Field Testing Training Manual (PAHO), tutorial for collaborative translation (CACE) and a tutorial for online coding (CEVECE).

In addition to the knowledge built, this experience allowed the network to help other Spanish speaking countries in the 2017 phase on the ICD-11 field testing and in the process of transition from ICD-10 to ICD-11.

**Lessons learned**

The experience of collaborative translation of the ICD-11 chapters has allowed 28 experts from seven Spanish speaking countries to participate in the project.

Most participants work in university health centers. Their knowledge and expertise in disease classifications is used by HIM professionals in their daily work and were essential to assure the best results in this activity.

The collaboration in this translation project has provided a large amount of knowledge in the following ways.

**Strengths**

**Honorific activity**

Participants were chosen between professionals who had experience in the use of medical terminology, mostly members of the Spanish Society of Medical Documentation (SEDOM) and the scientific societies of HIM at regional level. Therefore, the curricular prestige that the professionals contribute to the project is high, without having received any compensation for their work.

**Enable teamwork and sharing of knowledge and experiences**

The experience has been very enriching and rewarding due to the exchange of knowledge between the different participants at all levels. Agreements have been reached within the translation team of each chapter, subsequently with the reviewer of each chapter, as well as between the translators and reviewers of all chapters.

**Commitment: one year of intense work together despite thousands of kilometers distance and time zone difference**

The translation results have been made jointly despite the great distances between experts located in countries of different terrestrial hemispheres. This has been possible thanks to the powerful project coordination and virtual meetings with the follow-up of the assigned tasks. Technological means of communication provided, and daily work were also key tools. Furthermore, different training materials were used as video tutorials, slide presentations and informative emails.

**In the process of translation, the CCs made an effort to find a neutral language to be used in all Spanish-speaking countries**

Experts have been prone to reach agreements, with the ultimate goal to obtain terms that could be used in all Spanish-speaking countries.

**Have information about the ICD-11 features**

The ICD-11 will provide the users with more detailed and specific codes in addition to the inclusion of the new ones that can have a positive impact on health statistics. Alignment with other classifications is welcome. Its readiness to be used with electronic health records is a plus.

**Limitations**

**No funds assigned for this activity**

Experts voluntarily participated in the initial translation. Consideration of funding translation activities may be required for future updates, as well as to analyze the implementation in different countries.

**Overload of work for CCs**

Probably related to the previous point due to the lack of funds for this task, the translation has taken a year. As already mentioned, the participating experts have stable jobs, and their voluntary participation is an added task to their working hours.

**Frequent changes in the ICD-11 Beta draft after translation, platform and delays in the field testing**

This has required continuous learning by the group of experts according to the new additions of the material to the platform, which extends the time for completion of translations.

**Vocabulary innovations with no correspondence in Spanish**

This is a known drawback in all fields of translations. Therefore, agreements reached have been necessary to conclude the project.

## Conclusion

While the time and expertise applied to create the Spanish translation is great, the rewards can be equally high. As organizations prepare for ICD-11, the value and rewards must be considered to advance health and healthcare.

- A collaborative translation can be an enriching and rewarding experience for HIM professionals in order to exchange their knowledge at all levels.

- A powerful coordination of the project is mandatory to assure a good result.

- Technology makes it possible nowadays to collaborate in spite of the distance by different means (virtual meetings, training materials, etc.).

- As a reference terminology, it is very important to find a neutral language to be used if there are territorial variations.

- HIM professionals' expertise is essential to assure a positive impact on health statistics of ICD-11 in the near future in every country using every language.

- It is advisable to allocate specific resources for a task like this to obtain timely and quality results.

## About the authors

**Gemma Gelabert Colomé** MD. Chief of Clinical Documentation & Medical Records Department. Hospital Sant Joan de Déu, University of Barcelona. Esplugues de Llobregat, Barcelona, Spain. Gemma is also vice-president of Spanish Society of Medical Documentation (SEDOM).

**Artur Conesa González** MD PhD. Chief of Clinical Documentation & Medical Records Department. Hospital Clinic, University of Barcelona. Barcelona, Spain.

### References

1. *Gawryszewski; Mazas; Jimenez; Hernandez; et al. The experience of collaborative translation of ICD-11 Beta Draft into Spanish. WHOFIC-2015 Poster Booklet. Poster C315. https://www.who.int/classifications/2015_WHOFIC_Poster_Booklet.pdf*

2. *Gawryszewski, et al. The collaboration of the Spanish-speaking countries in the 11th revision of ICD (ICD-11). WHOFIC-2016 Poster Booklet. Poster C307.https://www.who.int/classifications/network/meeting2016/2016_Revision_Conference_Poster_Booklet.pdf?ua=1*

3. *Estandarización mundial de la información de diagnóstico en el ámbito de la salud, https://icd.who.int/es*

4. *ICD-11, International Classification of Diseases 11th Revision, The global standard for diagnostic health information, https://icd.who.int/en*

# Case Study - The WHO-FIC Education and Implementation Committee (EIC) Case Study

Sharon Baker

Vera Dimitropoulos

## Introduction

The World Health Organization-Family of International Classifications (WHO-FIC) Education and Implementation Committee (EIC) has in the past seen many Health Information Management professionals (HIMs) elected to chair and take on secretariat duties by the WHO-FIC Network. This is mostly due to recognition and acknowledgement by the WHO-FIC Network of the HIM professionals' knowledge and experience in education initiatives and implementation strategies associated with health classifications around the world.

The EIC assists and advises the WHO and the WHO Family of International Classifications (WHO-FIC) Network in implementing WHO classifications, with a principal focus on reference classifications. 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 WHO member states. Through the development and delivery of a Strategic Work Plan (SWP), the EIC plays an integral role in supporting the WHO in education and implementation activities for the International Classification of Diseases (ICD) and the International Classification of Functioning and Disability in Health (ICF). More recently, the EIC has had a major role in education and implementation activities ICD-11 for Mortality and Morbidity Statistics (ICD-11) as discussed in the section "ICD-11 Adoption and Implementation Strategies."

## Problem Statement/Background

EIC sub-groups have been established to finalize some outstanding tasks on the EIC SWP. There are a significant number of HIM professionals from around the world that participate and contribute to the work of the EIC sub-groups whose tasks include:

1. Finalizing the development and coding of term sets and scenarios in ICD-11 for ICD Field Implementation Tool (ICD-FiT).

2. Preparation of the use case for the new WHO-FIC Implementation Database (being developed by the WHO Classification Team) as well as the development of a succinct questionnaire template on implementation (ICD-11, ICF and ICHI) for the WHO-FIC Implementation Database. This EIC sub-group is to also provide detail on the output requirements of the WHO-FIC Implementation Database.

3. Establish a gold standard for WHO-FIC education materials and review and update international assessment/certification strategies. The work of this group includes:

   › Development of performance criteria/algorithm for creating new education materials as well as for the assessment of existing materials with a focus on ICD-11 curricula development.

   › Identification of international clinical coder competencies for both mortality and morbidity.

   › Development of morbidity exam questions and scenarios for ICD-FiT including a review and re-coding of the ICD-10 training material into ICD-11.

   › Development of mortality case scenarios for identification and coding of causes of death applying the ICD-11 mortality rules.

   › Development of a sustainable process for clinical coder recertification exams for both mortality and morbidity.

   › Revamping the WHO-FIC Trainer database in light of ICD-11.

## Discussion and recommendations

Since the annual WHO-FIC Network meeting that took place in Seoul, Republic of Korea in October 2018, the EIC has had two co-chairs and a secretary who are senior HIM professionals. Earlier EIC leadership also hailed from the HIM profession.

They have significantly contributed to the development, education and implementation of health classifications within their respective countries as well as internationally. During the past two years, the EIC has achieved a number of milestones in its Strategic Work Plan (SWP) to date. These include:

1. Finalization of the ICD-11 Transition and Implementation Guide.

2. Development and Implementation of a new EIC Website for EIC Members and Observers, as well as a public facing page. The Website hosts various important WHO-FIC resources which have been developed (e.g., Beta Version of the ICD-11 electronic training tool) or reviewed and updated (e.g., WHO-FIC Information Sheets) by the EIC.

3. Review and feedback to WHO regarding an update to WHO-FIC content on the WHO website.

The EIC still has much work to do in achieving the outstanding tasks within its SWP. Therefore, EIC work groups have been established to progress the work, coming together regularly through videoconferencing with assistance and guidance required by the EIC Secretariat and WHO Team.

## Conclusion

The EIC tasks to date have been completed largely involving collaborative efforts between HIM professionals and clinicians. This has resulted in the much needed resources and tools to assist countries with ICD-11 education and implementation strategies. Through its sub-groups, the EIC is on track to deliver on task 1 (mentioned in the Problem Statement/ Background above). This task requires HIM expertise in clinical coding and includes the final ICD-11 Term Sets for ICD-Fit with the introductory and moderately difficult term sets already finalized. The complex ICD-11 term set is near completion and was delivered to WHO prior to the annual WHO-FIC Network meeting in October 2020.

Other EIC sub-groups working on tasks 2 and 3 (mentioned in the Background statement above) require significant input from the WHO Team prior to their commencement. The bulk of this work was discussed and mapped out during the WHO-FIC Annual Network Meeting in October 2020.

The EIC will continue to work with its subgroups to progress the outstanding tasks on the SWP to ensure support to WHO in the development of education and implementation strategies as we move towards the international implementation of ICD-11, the modernization of the ICF and the finalization of ICHI.

## About the authors

**Sharon Baker,** ACC [UK], CTSS is a seasoned health information management professional with over 29 years of experience in clinical coding, decision support and management in health care settings in Canada and Wales. She is currently Manager, Classifications and Terminologies – Development with the Canadian Institute for Health Information where she is responsible for the assessment of ICD-11 for use in Canada. Sharon is the Co-Chair of the WHO-FIC Education and Implementation Committee. Contact information: sbaker@cihi.ca

**Vera Dimitropoulos** is an honorary research affiliate in the School of Health Sciences, Faculty of Medicine and Health at the University of Sydney. Up to the end of 2019, Vera was the Co-Director at the National Centre for Classification in Health, The University of Sydney. She was elected Co-Chair of the Education and Implementation Committee within the World Health Organization's Family of International Classifications (WHO-FIC) Network in Seoul, Korea in October 2018. Vera has also worked on ICD-11 as part of the International Joint Task Force which ended its mission in Seoul.

### References

1. *WHO Family of International Classifications Network, WHO-FIC Committees and Reference Groups, https://www. who.int/groups/who-family-of-international-classifications-network/committees*

2. *World Health Organization-Family of International Classifications (WHO-FIC) Network, https://www.who.int/ docs/default-source/classification/who-fic-network/frameworkforthewhoficnetworkstrategicplan20182023. pdf?sfvrsn=82ba073e_2*

## IFHIMA ICD-11 Whitepaper Working Group

Zahyiah AlAmry

Azza Mohamed Badr

Sharon Baker

Sue Bowman

Ann Chenoweth

Gemma Gelabert Colomé

Megan Cumerlato

Dilhari DeAlmeida

Maria Diecidue

Vera Dimitropoulos

Catherine Eastwood

Artur Conesa González

Gemala Hata

Joon Hong

Carol A. Lewis

Deneice Marshall

Jayeoba Olufunke

Guillermo Paluzie

Margaret Skurka

Sue Walker

Valerie Watzlaf

Yukiko Yokobori

### Disclaimer

*This whitepaper reflects the views of the International Federation of Health Information Management Associations (IFHIMA), and not necessarily its sponsors, partners, affiliates or members. This whitepaper offers no legal nor consulting advice. IFHIMA is not responsible for actions taken as a result of reading or using the whitepaper. IFHIMA is not liable for the contents of external links. Responsibility for external links belongs to their operators.*