An ICD for the Digital World: What Does the ICD-11 Research Show?

Susan H FENTON[a,1], Mary H. STANFILL[a] and Kathy GIANNANGELO[b]

[a] *The University of Texas Health Science Center at Houston, Houston, Texas, USA*

[b] *Kathy Giannangelo Consulting, LLC*

ORCiD ID: Susan H. Fenton https://orcid.org/0000-0003-2943-311X

Abstract. The 11th revision of the International Classification of Diseases (ICD) is now available for use. A literature search was conducted to review and summarize the research conducted to date. In addition to the ease of integration into electronic health records using standard digital tools such as uniform resource identifiers and application programming interfaces, ICD-11 and the World Health Organization provided linearization for mortality and morbidity, ICD-11-MMS, promise improved backward compatibility to ICD-10; increased availability in multiple languages; greater detail for clinical use, including traditional Chinese medicine; and enhanced maintenance for continued relevance. The studies reviewed here support the superior content and utility of ICD-11-MMS. Meaningful planning for implementation has begun, including the provision of a framework. It is time for the world to adopt a digitally prepared ICD.

Keywords. ICD-11, implementation, digital health

1. Introduction

The International Classification of Diseases (ICD) has been the international standard for comparing causes of mortality and morbidity for more than 100 years [1]. In May 2019 the 11 revision, also known as ICD-11, was approved by the 72nd World Health Assembly for implementation beginning in January 2022 [1,2]. As multiple publications point out, ICD has been updated for the 21st century [1-3]. This is an examination of exactly what makes ICD-11 unique, research that is ongoing related to adoption, as well as findings important for the ultimate implementation and use across the globe.

2. Methods

A literature review of PubMed was conducted using "ICD-11" and "research" and "adoption" as search terms. The timeframe was limited to publications more current than 2010. A total of 288 citations were returned. After reviewing titles and abstracts the full-text for 35 publications was retrieved. Upon further review of the full-text, 15 peer-reviewed publications are included for this paper.

[1] Corresponding Author: Susan H. Fenton, PhD; Tel: +1 210-332-3525, email: susan.h.fenton@uth.tmc.edu.

3. Results

3.1. Design and Development

Our world has changed significantly since the 10th revision of ICD was released. The world wide web has become ubiquitous, transforming how we communicate and exchange data. Consequently, the ICD of today must be computable, flexible, multi-lingual, and clinical at its core. These tenets have resulted in a revolutionary ICD-11.

The first essential tenet is that of computable. While not all health care systems are computer-based, the tipping point is near or has been reached. ICD-11 was created with a knowledge framework that enables its use in different digital health information systems [1]. This framework includes the Foundation database, or the universe of ICD concepts, supported by a content model to ensure longitudinal stability [1,4,5]. The Foundation is supported by an ontology. Haendel and colleagues state that "ontologies define relationships between concepts in a way that allows computational reasoning…" [6] The framework also creates what are known as linearizations, or subsets of the Foundation, such as the ICD-11 for Mortality and Morbidity Statistics (ICD-11-MMS) with unique properties and characteristics that allow it to be used for the purpose of statistical classification. In addition, support for digital use is included in the form of Uniform Resource Identifiers (URIs) and application programming interfaces (APIs) [1].

The second tenet is for ICD to be flexible. We actually have a superb example of this flexibility shortly after approval with the emergence of COVID-19. We also see this flexibility in the maintenance and feedback options available. Never before has there been a year-round, open, and transparent revision process where literally anyone with an interest is able to suggest changes to ICD. In addition, ICD-11's versatility is represented by it numerous uses [7] all coming from a common base. This flexible classification can accommodate country specific modifications and integrate with other classifications and terminologies.

Third, we have the tenet of multi-lingual. As of the 2022 release, ICD-11 is available in WHO's six official languages, Arabic, Chinese, English, French, Russian, and Spanish. A reported 20 additional languages are in the process of translation [8]. WHO also provides a platform allowing for collaborative translation, another first for ICD.

The final tenet to be discussed here is that of clinical relevance. Of course, it is absolutely essential that ICD represent all that is clinically relevant both for mortality and morbidity. Thus, given the fast-paced nature of discovery and change in health care, it is not reasonable to expect a static system to remain relevant for 10 or more years. Hence, the Foundation, the maintenance plan including the establishment of the Medical and Scientific Advisory Committee, and the introduction of post-coordination, will ensure that ICD continues to evolve to meet current and future needs.

3.2. New to ICD-11

The content of ICD-11 has been dramatically altered. The first item of substantial note is the inclusion of traditional and complementary medicine. As Lam and colleagues note, this decision recognizes the importance of traditional Chinese medicine (TCM), is responsive to the member states where TCM is common, and brings TCM and western medicine closer together [9]. This expanded scope allows for dual coding of TCM and western medicine diagnoses. The second addition is that of rare diseases with a unique

URI. As Chute conveys in his 2018 paper, the clinical description for rare diseases is expected to expand as more is understood about rare disease etiology and genomic expressions [4]. A third upgrade is the addition of Extension codes, currently over 20,000 [1], which may originate from WHO terminologies.

3.3. Comparing ICD-10 to ICD-11

Of course, the world cannot contemplate a move to ICD-11 without a consideration of ICD-10. WHO itself addresses this need for comparability in the 2019 Implementation Guide[10]. While acknowledging the need for maps or crosswalks, they explicitly state that some loss of information between two classification systems is to be expected [10].

Several researchers have explored this issue. In Poland, Krawczyk and Swiecicki reviewed the proposed changes, paying particular attention to the subchapters related to mental health [11]. They specifically noted the reorganization of ICD-11, but also that disorders not included in ICD-10 were found in ICD-11. German and Italian researchers collaborated to explore the impact of the need for translation on the Iris software that is used for the automated coding of causes of death [12,13]. This translation was felt to be feasible.

In the United States, the comparison has included ICD-10, but has also focused on differences and similarities between ICD-10-CM (the U.S. clinical modification) and ICD-11. Three studies have been completed. The first study focused on comparing the number of codes, as well as identifying equivalent codes [14]. The overall findings were that ICD-11 had a moderate increase in the number of codes over ICD-10. Additionally, when postcoordination is used, approximately 60% of the 388 ICD-10-CM codes examined could be fully represented [14]. The second study focused on patient safety and clinical quality measurement use cases for the ICD-11-MMS compared to ICD-10-CM [15]. Generally, greater detail is captured by ICD-11-MMS for both use cases [15]. Finally, the third study specifically examined whether it would be feasible to replace ICD-10-CM for morbidity reporting with ICD-11-MMS [16]. The study assessed 943 frequently used ICD-10-CM codes and found that nearly 60% could be fully represented in ICD-11-MMS with postcoordination and minor enhancements.

3.4. Implementation

Of course, the many countries are concerned about implementing this new system, especially given the use of cluster coding or postcoordination. The Ministry of Health in Kuwait led the world by pilot testing ICD-11-MMS for morbidity data collection and reporting in the real world [17]. Conducted from April to July 2021, 241 physicians participated and coded 3,903 inpatient discharges. Nearly half (46.5%) of the exact diagnoses were found, with 47.1% saying the ICD-11 entity was fairly easily found, in an acceptable timeframe (46.5%) [17]. Although the situation will be different in each country, this pilot demonstrates that ICD-11 can be integrated into an EHR and used for morbidity code assignment.

A consideration for many countries is the impact on costs and outcomes in order to make informed decisions. This is especially important since so many stakeholders remember the transition to ICD-10 and its various modifications regardless of when it occurred. A group of Canadian researchers developed a methodology to evaluate the impact of ICD-11 adoption [18]. Though this publication did not actually estimate the

costs of a conversion, it did group the expected costs into three categories: retraining costs, productivity losses, and system change costs [18].

The WHO does provide multiple tools and guides to assist in implementation, including an implementation and training guide [10], reference and user guides [19,20], as well as the API, browser, and coding tool [7]. Countries across the world are engaged in planning.

4. Discussion

With the essential tenets, computable, flexible, multi-lingual, and clinical at its core, ICD-11 has from its beginning been designed and developed from a computer science perspective with a goal of health information systems interoperability. ICD-11's capabilities to integrate other terminologies and classifications increases its scope and far exceeds the ICD-10 "one size fits all" classification. However, the findings from different countries suggest that ICD-11-MMS has maintained good backward comparability to ICD-10. This will support longitudinal reporting and may make any transition easier.

In addition, ICD-11 with its newly established framework that includes a well-defined and cross-linked network of disease concepts delivers a structure that may eliminate the need for country specific modifications. For those impacted, this is an implementation issue in need of early resolution to expedite ICD-11 adoption. Detailed research in country about the costs and benefits of transition or implementation is also necessary.

5. Conclusions

The Kuwait pilot illustrates ICD-11's ability to integrate with EHRs. Other research supports ICD-11 having more meaningful clinical content than ICD-10. WHO's multiple tools and guides are expected to reduce the costs of training and implementation. With a multilayered process involving many stakeholders, ICD-11 adoption requires careful planning. Research findings, such as those described, are imperative for successful preparation across the globe. This is truly an ICD for digital health in the 21st century.

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