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# **Authors**

Southern, Danielle A Hall, Marc White, Deborah E <u>et al.</u>

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Perspectives on Quality

# Opportunities and challenges for quality and safety applications in ICD-11: an international survey of users of coded health data

## DANIELLE A. SOUTHERN<sup>1</sup>, MARC HALL<sup>2</sup>, DEBORAH E. WHITE<sup>2</sup>, PATRICK S ROMANO<sup>3</sup>, VIJAYA SUNDARARAJAN<sup>4,5</sup>, SASKIA E. DROESLER<sup>6</sup>, HAROLD A. PINCUS<sup>7,8,9</sup>, and WILLIAM A. GHALI<sup>10</sup>

<sup>1</sup>Department of Community Health Sciences and the O'Brien Institute for Public Health, University of Calgary, Calgary, AB, Canada, <sup>2</sup>Faculty of Nursing, University of Calgary, Calgary, AB, Canada, <sup>3</sup>Division of General Medicine, University of California–Davis School of Medicine, Sacramento, CA, USA, <sup>4</sup>Department of Medicine, St Vincent's Hospital, University of Melbourne, Parkville, Australia, <sup>5</sup>Department of Medicine, Southern Clinical School, Monash University, Melbourne, Australia, <sup>6</sup>Faculty of Health Care, Niederrhein University of Applied Sciences, Reinarzstrasse 49, 48705, Krefeld, Germany, <sup>7</sup>Department of Psychiatry, Columbia University and the New York State Psychiatric Institute, New York, NY, USA, <sup>8</sup>Irving Institute for Clinical and Translational Research at Columbia University and New York-Presbyterian Hospital, New York, NY, USA, <sup>9</sup>RAND Corporation, Pittsburgh, PA, USA, and <sup>10</sup>Cumming School of Medicine, University of Calgary, Calgary, AB, Canada

Address reprint requests to: Danielle A. Southern, E-mail: dasouthe@ucalgary.ca

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### Abstract

**Objective:** In 2018, the World Health Organization (WHO) plans to release the 11th revision of the International Classification of Diseases (ICD). The overall goal of the WHO is to produce a new disease classification that has an enhanced ability to capture health concepts in a manner that is compatible with contemporary information systems. Accordingly, our objective was to identify opportunities and challenges in improving the utility of ICD-11 for quality and safety applications. **Design:** A survey study of international stakeholders with expertise in either the production or use of coded health data.

Setting: International producers or users of ICD-coded health care data.

**Study Participants:** We used a snowball sampling approach to identify individuals with relevant expertise in 12 countries, mostly from North America, Europe, and Australasia. An 8-item online survey included questions on demographic characteristics, familiarity with ICD, experience using ICD-coded data on healthcare quality and safety, opinions regarding the use of ICD classification systems for quality and safety measurement, and current limitations and potential future improvements that would permit better coding of quality and safety concepts in ICD-11.

**Results:** Two-hundred fifty-eight unique individuals accessed the online survey; 246 provided complete responses. The respondents identified specific desires for the ICD revision: more code content for adverse events/complications; a desire for code clustering mechanisms; the need for diagnosis timing information; and the addition of better code definitions to reference materials.

**Conclusion:** These findings reinforce the vision and existing work plan of the WHO's ICD revision process, because each of these desires is being addressed.

Key words: World Health Organization, International Classification of Diseases, quality indicators, patient safety

In 2018, the World Health Organization (WHO) plans to release the 11th revision of the International Classification of Diseases (ICD) [1]. Key components of the revision process are 'Topic Advisory Groups' (TAGs) [2], which 'serve as the planning and coordinating advisory body for specific issues that are key topics in the update and revision process' [3]. In addition to the vertical TAGs that have responsibility for specific sections of the classification (e.g. mental health, oncology), there are horizontal TAGs that focus on 'use cases' (purposes) that crosscut the sections of the ICD. The Quality and Safety TAG (QS-TAG) is one such horizontal TAG, with 18 members, that is charged with proposing concepts and defining terms to support the quality and safety use case for ICD-11 implementation. In early stages of its work, the QS-TAG undertook consultations with leaders of the WHO Family of International Classifications (FIC) network, including experts in the domains of mortality coding, morbidity coding, case-mix system development and ontology development. The information derived from these consultations, supplemented by the WHO's past experience in developing ICD-10, produced a QS-TAG work plan that we have described elsewhere [4].

To further inform the ICD revision process in the domain of quality and safety, we undertook a survey study of international stakeholders with expertise in either the production or use of coded health data. The primary goal of this survey was to solicit stakeholder perspectives on enhancements to the disease classification that, if implemented, could make ICD-11 more useful for quality and safety applications worldwide. The results are a necessary and valuable complement to the Q&S TAG's a priori work plan, guiding strategic directions for an enhanced ICD-11.

### Methods

### Sampling

A snowball sampling method was used for this survey study, with Q&S TAG members initiating subject identification. Each TAG member was asked to send an invitation by email to a minimum of 10 'health data stakeholders'. The targeted stakeholders were defined as coders, ontology/classification experts, researchers who utilize secondary datasets for quality and safety-related research, and clinicians with responsibility for administering quality measurement and improvement programs. To propagate the snowball sampling, invitation emails from Q&S TAG members asked stakeholders to forward the survey invitation to five additional people. In such an approach, the final number of survey recipients is unknown at the outset, although the a priori target was to obtain at least 150 responses from at least 10 countries.

### Survey content

An 8-item survey was created and posted online. The survey included demographic questions (country of primary professional activity, type of organization and role in organization) and a question regarding the respondents' self-rated familiarity with ICD. Respondents were also asked how often they currently use information on health system quality or safety derived from ICD-coded data for a variety of purposes and how useful the current ICD classification systems have been as tools for quality and safety measurement in their experience or the experience of their organization. Open-ended questions were included to identify (i) specific key limitations/challenges associated with the use of ICD-9 and/or ICD-10 in the measurement of quality and safety; and (ii) key elements and/or functionality that the subjects would like to see in an enhanced ICD-11 system that would permit better

coding of quality and safety concepts. The survey was administered, stored and managed using a commercial online survey tool maintained by Fluid Surveys<sup>TM</sup> (Ottawa, Ontario, Canada). The questionnaire was available online for a 3-month period between July and October 2013.

### Analysis method

### Quantitative data

Survey responses were downloaded and MS Excel was used to create bar charts and tables of aggregated responses. Data analysis was purely descriptive with simple reporting of means and proportions. Due to the sampling method and descriptive nature of our work, hypothesis testing was not performed.

### Qualitative data

Completed open-ended responses from the survey were imported into NVivo 10 for qualitative data management and theorizing. Data were coded and analyzed by an experienced qualitative researcher and research assistant. A coding framework was created through a process of independent review of responses and formulation of provisional themes and categories. The iterative process of data analysis and synthesis conducted by our team involved a bidirectional mapping of quotes to themes. This was undertaken collaboratively by the two members (D.W. and M.H.) who led data analysis activities in our qualitative descriptive study, and the mapping of quotes to themes was verified for face validity by remaining team members. Data were further analyzed by a process of induction to transform data from individual open text responses to common, interactive themes involving coding, categorizing and conceptualizing [5, 6].

### Results

### Study sample

Two-hundred fifty-eight unique individuals accessed the online survey, among whom 246 provided complete responses. Of these, 161 (67%) of the responses were from stakeholders located in North America, 61 (25%) from Europe, 18 (7%) from Australia and 3 (1%) from Singapore.

### Quantitative description

Thirty-five percent of respondents were 'extremely familiar' with ICD coding and <10% reported being not very familiar (a response of four or lower). Figure 1 displays the type of organization and professional roles of respondents. The majority (88%) of respondents worked at healthcare delivery organizations, government organizations, regional health authorities, universities or research institutes. Their roles were as analysts, coders, researchers, program leads and senior management.

Figure 2 outlines how respondents use ICD-coded data for different purposes. These data are most often used by respondents in quality reporting, quality improvement and research. Consistent with this perspective, the majority of respondents highly rated the usefulness of the ICD classification system as a tool for quality and safety measurement (i.e. scores of 7 or higher on a 1–10 scale).

### Qualitative analysis of open-ended questions

Table 1 presents extracted themes and selected quotes from responses to the open-ended questions on limitations of ICD and key recommendations for ICD-11. Column 1 identifies the themes and/or subthemes

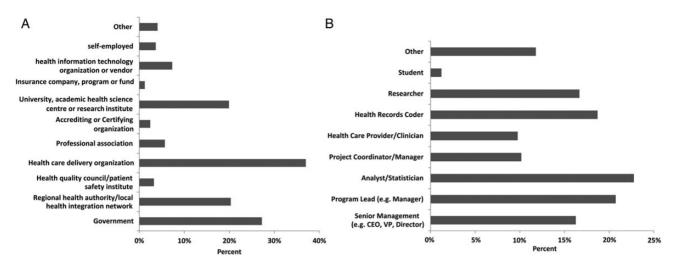


Figure 1 The organizations in which respondents work and their roles in those organizations. (A) Type of organization. (B) Role in organization.

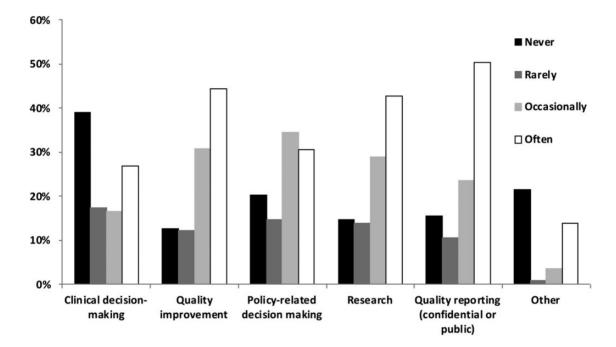


Figure 2 Respondents' use of information on health system quality/safety derived from ICD-coded data, by purpose.

identified through qualitative analysis. Column 2 provides a definition of the theme according to survey participants' responses.

Three key themes emerged from the data: (i) technical issues; (ii) content problems; and (iii) training needs. We expand on each of these below with representative quotes from participants.

### **Technical issues**

Stated limitations of ICD-9 and ICD-10 revolve around the design or mechanics of coding: specifically, the lack of ability to cluster-related diagnoses, the lack of optimal compatibility between older and newer versions of ICD, the potential lack of clear mapping between ICD and other reporting systems, and a variety of other technical challenges with coding.

Many participants identified that a major limitation in ICD is the 'inability to link concepts through clustering'. This problem is widely viewed to be a challenge because of 'the way it [the classification system] is scattered now [making] it harder to be exhaustive and to be sure [we are] using the most specific code'. Clustering would 'enable the capture of the complete clinical picture', which would 'benefit the quality improvement efforts and could improve care'.

Participants spoke to concerns related to the introduction of new versions of the ICD. They articulated that there would be a need for robust 'crosswalks between ICD-9, ICD-10 and ICD-11'. In this same vein, they indicated challenges associated with 'coding rules that keep changing, new procedures, approaches, etc. that are not included in the look ups'. They emphasized the need for good information tools to inform users about new coding rules and standards.

Several other participants indicated that there should be a link or crosswalk between the ICD and the global reporting system of SNOMED [7], which provides a comprehensive and multilingual

Themes/sub-themes	Definition	Limitations/challenges (Question 7)	Recommendations (Question 8)
Technical issues Clustering	The inability to link concepts/ codes	Problem with lack of ability to cluster Not being able to link/cluster codes In Canada, we were previously allowed to use clustering for any type of codes and we used them to link trauma codes with their respective external cause code. This was very helpful, but clustering is now restricted to use with Y40 to Y84 and U82 and U83	Clustering of concepts would be very helpful to perform thorough search. The way it is scattered now makes it harder to be exhaustive, and to be sure to be using the most specific code Use clustering to enable the capture of the complete 'clinical picture', i.e. link all diagnosis associated with the medical/ procedural complication Particular attention should be paid to 'Combination codes' that can span more than one chronic disease category
Different versions of ICD	Changes in the ICD make it difficult to have standard rules	Coding rules that keep changing, new procedures, approaches, etc. that are not included in the look ups How to ensure when changes to coding and the standards were implemented to ensure trending	Crosswalk between ICD-9, ICD-10 and ICD-11 It should be possible how ICD-10 and ICD-11 are linked. This is crucial when we want to understand how prevalence of a determinate disease has changed in time
Linkages with SNOMED	The need to link ICD to the global reporting system of SNOMED	Terminology not consistent with SNOMED CT terminology Inconsistency in terminology with terminology SNOMED CT; lack of sufficient mapping from SNOMED CT to ICD-10	Should be based entirely on SNOMED CT Consistency in terminology with terminology SNOMED CT; sufficient mapping from SNOMED CT to ICD-10-CM
Specific technical	Technical details about ICD coding that create challenges (i.e. character position, etc.)	Sometimes having the decimal point makes it challenging to have clean data entry It becomes a nightmare trying to fix all of the data errors where people put in the decimal, or do not put it in or use other characters Each code should have the character initial or secondary to better explain the taking charges	<ul> <li>Keep the 7th character info for Injury codes (ex A, D and S)</li> <li>Do not assign the same U code for so many different locations</li> <li>It would be necessary to have a letter (for example "S") added to the code to allow coders to input that diagnoses as a safety problem</li> <li>All procedure codes should have status attribute A-Abandoned. This would result in more precise reporting of started then abandoned procedures and fewer errors in applying the cancelled/change of plan/failed intervention coding standards</li> <li>Some code groups, such as N00-N08 (glomerular disease) are particularly challenging for coders. The terminology and Alpha Index lookups do not lead to matching terms in the Tabular Index (e.g. IgA nephropathy)</li> </ul>
Content problems Missing codes, info, or concepts	The ICD is missing codes, information, and/or concepts to identify certain clinical situations,	Missing codes and/or inclusion in a code Missing codes, especially for new technologies/procedures Missing concepts	Identifying missing codes Updated and better drug table listing many more drugs More postoperative codes
Clarification of terms and/or more details needed	diagnoses, etc. Codes and descriptions are not clear enough to properly and accurately code	Vagueness of descriptions leaves classifications open to interpretation. This results in inconsistent coding of same condition Would be helpful if there were coding examples Clarification of terms and examples would be beneficial	More detail in the diagnosis codes (especially the mental health codes) Better clarification of terms, they aren't intuitive at allMore precise description of diabetes Definition of the main manifestations included in diseases for non-medical coders

### Table 1 Common themes identified and selected quotes in the qualitative analysis of open-ended responses

### Table 1 Continued

Themes/sub-themes	Definition	Limitations/challenges (Question 7)	Recommendations (Question 8)
Specificity	Overall, codes are very broad	Overall lack of detailed codes that uniquely identify patient safety and quality issues. A lot of the patient quality and safety issues get lost in generic codes Key limitation of ICD-9 has been the lack of nuance of the codes; codes are too broad Granularity of information—Too general for clinical use in most contexts	<ul> <li>More specificity in codes - especially those that relate to quality indicators</li> <li>Lack of specificity of body parts (e.g. for wounds and ulcers)</li> <li>Less redundancy so that providers would be "forced" to choose from a limited number of codes for the same diagnosis. Even something as simple as cataracts grows into senile cataract, cataract bilateral, cataract, etc.</li> <li>Improve indicating the includes/excludes/ code also/code separately for diabetic coding</li> </ul>
Complications/ adverse events	Lack of coding to identify complications/adverse events	Consistent and promoted codes for complications, errors, iatrogenic harm etc	<ul> <li>Specific codes for patient safety and quality items—not to be thrown together with a bunch of other conditions</li> <li>Codes that reflect medical errors and/or system related errors (e.g. EHR caused errors)</li> <li>Better guidance to distinguish between pre-existing medical conditions and new complications or acute acerbations of prior conditions</li> </ul>
Severity	No codes that identify the severity of illnesses	<ul> <li>Missing information on severity of condition</li> <li>Inability to identify the level of severity of the disease like hypertension, heart failure, etc.</li> <li>Challenging to code COPD severity and difficulty with coding type of COPD</li> <li>Lack of consistent approaches to describing acuity</li> </ul>	<ul><li>For specific assessment of severity of cases and complications</li><li>Mild, moderate or severe, a graded code of the level of comorbidities</li><li>More flexibility in the codes to capture severity of quality/safety</li><li>Able to express concepts as chronic/acute, complications</li></ul>
Training needs Standardization rules and documentation	Standardization rules and appropriate documentation and reporting to support consistent coding	<ul> <li>More visible rules to limit their interpretations</li> <li>Need for more precise coding rules</li> <li>Vagueness of descriptions leaves classifications open to interpretation. This results in inconsistent coding of same condition</li> <li>Inadequate documentation to support appropriate/specific code selectionConflict in documentation on causal relationship of care to complication. E.g. Hypotension occurring after surgery. Documentation is often vague regarding causal link</li> <li>Coding standards are not always clear: need for clarification of terms</li> <li>Conditions arising as a result of healthcare, complications of medical and surgical care need additional coding rules to guide coders</li> <li>Stakeholders often do not understand the coding rules and concept</li> <li>Physicians and coders do not agree on how to use the codes, the more codes we have the less they agree, but with fewer codes there is less precision</li> <li>Providers (physicians) not choosing the correct codes</li> </ul>	<ul> <li>Coding rules that would create better standardization</li> <li>Need for [clearer and specific] coding rules that constrain performance</li> <li>Rules that are clearer, more standardized</li> <li>Documentation may not be clear to allow accurate coding and/or codes may be limited in being able to capture the specifics of the case</li> <li>Rules to assure standardization across all health care entity reporting</li> <li>Standardization of terminology and rules, so that clinicians/coders and ICD-11 all speak the same language</li> <li>Would like to see increased standardization and a better link with providers. I believe there is often a disconnect between what is documented and coding</li> </ul>

clinical terminology for healthcare. Participants indicated that current ICD 'terminology [is] not consistent with SNOMED CT terminology'. Another respondent recommended that ICD 'should be based entirely on SNOMED CT'.

A variety of other specific technical issues were identified by participants. These included concerns that decimal points in ICD codes are sometimes used incorrectly, and recommendations for use of a 7th digit code in ICD data to capture concepts such as laterality and diagnosis timing (i.e. concepts that currently exist in ICD-10-CM, the US modification of ICD-10 for morbidity coding).

### Content problems

Respondents pointed to a number of content problems in previous versions of the ICD. Many participants spoke of 'missing codes and/or inclusion elements in a code' and 'missing concepts'. Participants also identified a need for clarification of terms and/or more detail indicating there is 'not enough detail in some of the code areas [making] it difficult for quality data collection'. The 'vagueness of descriptions [lack of detail] leaves classifications open to interpretation, resulting in inconsistent coding of the same condition'.

Specificity in the coding scheme was also seen to be important. In particular, codes were described as sometimes being 'too general for clinical use in most contexts' and alluding to a 'lack of specificity and sensitivity of [some] codes'. One participant noted that these challenges are magnified when working across versions, stating 'ICD-9 is limited in scope, whereas ICD-10 is so large that more finite indicators need to be developed to address the level of specificity required'. Some areas identified as needing more improvement in specificity include: 'localizing body parts (e.g. for wounds and ulcers)'; 'peadiatrics (sic) [in general]'; 'those that relate to quality indicators'; and 'diabetic coding'.

Of great relevance to the quality and safety use case, many respondents highlighted the shortcomings of existing complication and/or adverse event codes in ICD-9 and ICD-10, as well as recommendations for the coding of these events in ICD-11. Specific concerns included that there is 'missing information to indicate a condition as adverse event' (sic) and that 'external cause codes in both versions lack specificity when it comes to injuries due to errors'. Specificity was also reported to be an issue with hospital-acquired infections. Some participants reported a desire to see the inclusion of 'specific codes for patient safety and quality items', rather than having codes appear interspersed among other conditions.

There was also concern expressed around the fact that 'the severity level of diseases, pathologies and comorbidities is rarely available in ICD-10'. Similarly, qualifiers such as 'chronic vs. acute exacerbations for conditions such as hypertension and heart failure would also be helpful'.

### Training needs

Training needs identified by participants included having standardized rules and practices on coding, reporting, and documentation. Participants identified a strong 'need for more precise coding rules' so that everyone is coding consistently. They mentioned that the 'vagueness of descriptions leaves classifications open to interpretation. This results in inconsistent coding of the same conditions'. Specific to ICD-10, there are 'no set coding guidelines available'; 'coding rules create better standardization, consistency and comparability'. One participant explained that 'coding rules are already quite complex and there is much relying on coder interpretation of these rules - perhaps more support for computer-assisted coding or more interactive training opportunities for coders [would be beneficial]'. More training on how to report and document was identified as a need because 'poor documentation leads to inability to assign appropriate codes'. Participants identified that this seems to be a problem at the frontline: 'Stakeholders often do not understand the coding rules and concepts', 'Physicians and coders do not agree on how to use the codes'. Respondents recommend 'standardization of terminology and rules, so that clinicians/coders and ICD-11 can all speak the same language'. One respondent recommended 'rules to assure standardization across all health care entit(ies) reporting'.

### Other comments from respondents

Another concern raised by respondents related to the financial motivations that often underlie the use of ICD. Participants expressed concern that 'coding is too billing driven or at best driven by government mandates of process measures'. Other views expressed included: 'Changing the culture of using ICD codes for quality not just for reimbursement'; that '[users] are victims of our fee-for-service payment system in that docs list as many codes as relevant to maximize reimbursement and hence their utility for quality metrics becomes limited'. In stating these latter concerns, respondents did not give concrete recommendations on how to overcome these challenges.

### Discussion

This survey targeted stakeholders who were classification experts, researchers who utilize secondary datasets for quality and safety-related research, and clinicians and/or health system leaders with responsibility for administering quality measurement and improvement programs. The respondents were experienced users of the ICD and, based on their responses, appear to believe in the power of ICD-coded data. Nonetheless, through this survey, the respondents identified a number of key challenges with existing ICD data, and provided ideas for their enhancement.

The respondents identified a need for more code content related to adverse events and complications, expressed a desire for code clustering mechanisms and diagnosis timing variables, and requested better code definitions. These findings reinforce the vision and existing work plan of the Q&S TAG, which is described in detail in earlier publications [4]. The desires of the respondents align closely with the multifaceted work plan of the Q&S TAG, which includes: (i) development of a new information model and coding options for healthcare-related adverse events; (ii) refinement of coding rules for diagnosis timing [8, 9], code clustering, and main condition; (iii) development of explicit definitions for most healthcare-related harm concepts; and (iv) removal of some problematic or redundant content that previously existed in ICD-10 in the domain of healthcare-related adverse events. These planned changes should enhance the usefulness of ICD-11 for quality and safety applications [10]. For example, diagnosis clustering in ICD-11 will permit better coordination and linkage of diagnosis concepts in hospital discharge records and therefore enrich the ability of ICD-coded data to capture health-related injury episodes that may involve several related concepts or events.

Our survey study used a snowball sampling method. This method can produce non-representative study samples. Indeed, with the starting point for our survey being Q&S TAG members, the resulting snowball sample is a group of individuals who are predominantly based in developed countries, with considerable expertise in relation to coded health databases. For the purposes of this study, such a sample is actually quite desirable, because we are seeking the views of invested stakeholders. We received responses from 258 interested individuals with a diverse range of expertise in ICD-coding, and we noted saturation of extracted themes, so our findings appear to cover the improvement needs of stakeholders in developed countries. As with all qualitative analyses, there is some subjectivity involved in the identification of themes, and their mapping to representative quotes. That inherent limitation is mitigated by our use of a combination of quantitative and qualitative analyses. Quantitative analyses have the benefit of describing the proportions of individuals with given opinions. Qualitative data, meanwhile, provide a depth of information through unstructured and open-ended questioning.

This paper has identified the views and wishes of informed health data stakeholders for a revised and enhanced ICD, embodied in ICD-11. The survey responses, obtained and compiled in 2014, validate the Q&S TAG work plan that we have devised and undertaken over the last 2 years. Through the creation of standing committees such as the Q&S TAG, and the associated ICD-11 field trial process, the WHO is seeking to obtain stakeholder input into novel features that will produce an effective and enhanced disease classification in ICD-11. The survey research described here has significantly informed the revision process.

The original work plan for the Q&S TAG was initially devised in early 2010, and it has been formally described in a recent publication from the Q&S TAG [4]. Significant progress has already occurred on the work plan described in that paper. Coding rules for the main condition, diagnosis timing and clustering are in place and ready for official launch in ICD-11, and a new way of capturing healthcare-related adverse events has also been developed in the current beta version of ICD-11 [11]. Collectively, these new developments address many of the stated desires of the stakeholders who responded to the survey, with the ultimate benefit being enhanced international health data, embodied in the new ICD-11, to support global efforts for improving quality and safety in health care.

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