Comparing ICD-data Across Countries: A Case for Visualization?

Lucia Otero Varela[1]*, Søren Knudsen[1,2]†, Sheelagh Carpendale[1,3]‡, Catherine Eastwood[1]§, Hude Quan[1]¶

[1]University of Calgary, [2]University of Copenhagen, [3]Simon Fraser University

ABSTRACT

We present our preliminary results of an international survey on the practical adoption and use of the International Classification of Diseases (ICD) from a visualization and visual analytics perspective. The ICD system, in different versions, is globally used for coding morbidity and mortality statistics, however, coding practices vary across countries. Our survey includes questions about hospital data collection systems, use of features in ICD, and training of ICD coding specialists. Variations in ICD could hinder comparability and limit generalizability of observed findings. Our preliminary results establish the current state of ICD use and training internationally, and will ultimately be valuable to the World Health Organization to further research on how to improve ICD coding, and enhance international comparisons of health data. From a visualization and visual analytics perspective, the current differences in adoption and use of ICD poses challenges and opportunities. For example, when morbidity-data from two countries differ in their coding, can we still compare data from these countries, and if so, then under which circumstances? We discuss how visualization and visual analytics might help in these situations.

1 INTRODUCTION

In the visualization community, a recent discourse has emerged centering on the understanding that data is created, and cannot be taken for granted [3, 5, 7]—that data is never objective. Similarly, in a healthcare context, data is created and made sense of in a variety of different ways. For example, from clinical professionals' use of the medical chart as a narrative resoning-device [2], over administrative support staff's role in patient triaging [8], to healthcare researchers' carefully crafted clinical studies.

Seeking to enable comparisons of healthcare data across countries and different clinical contexts, the World Health Organization (WHO) developed the International Classification of Diseases (ICD) [13]. This international and multilingual reference standard is used to measure health and health services (such as morbidity and mortality statistics, quality and safety, health care costs, and clinical research) by multiple professionals, in different health care sectors [12].

Data generated at every patient encounter with the healthcare system contains rich clinical and health services information that is abstracted (by coding professionals) and coded, using ICD, into administrative health datasets (Figure 1). Although initially collected for administrative and billing purposes, ICD-coded data have been increasingly and widely used for secondary purposes, such as epidemiological studies, disease surveillance, decision- and policy-making, as well as administering health services to ultimately improve population health [1].

*e-mail: lucia.oterovarela@ucalgary.ca
†e-mail: sknudsen@ucalgary.ca
‡e-mail: sheelagh@sfu.ca
§e-mail: caeastwo@ucalgary.ca
¶e-mail: hquan@ucalgary.ca

However, while the WHO aims for ICD to support standardisation across countries, differences in how healthcare professionals use the classification leads to semantic differences. The structure of healthcare personnel across countries might increase these differences. While dedicated staff in one country is tasked with coding medical charts, that same task is performed by physicians in another. Additionally, countries have adopted national extensions to current standards, and what was intended as a standardisation effort, seems more like a quilt of patchwork.

Despite attempts by the WHO to regulate the modifications of ICD-10 (the most common version in current use), differences between countries have arisen as a result of adding more clinical codes to increase the level of detail [4], or simplifying ICD-10 for use in developing countries [9]. The development of clinical modifications led many to be concerned about the impact on the future comparability of morbidity data, as heterogeneity of data can hinder meaningful comparisons and limit generalizability of observed findings [6]. To address these issues, the WHO has now released the 11th version of ICD (ICD-11), with enhanced usability, increased comprehensiveness, more clinical detail, and updated scientific content [12].

We conducted a survey on hospital data collection features and the training of coding specialists across 26 countries to establish the current state of ICD use and to better understand the differences in coding practices. We briefly describe our preliminary results and discuss how visualization and visual analytics might be an answer to alleviating these current shortcomings, as well as how they might play a role in more standardised use of ICD in the future, for example, in adopting ICD-11.

2 DATA COLLECTION FEATURES

National hospital morbidity databases compile information on the patient's encounter with the healthcare facility, from admission to discharge, including diagnoses and procedures. However, differences exist between countries in regards to how these data are collected from medical charts.

Number of coding fields for diagnoses and procedures: All surveyed countries have at least one field for diagnoses and one field for interventions (i.e. coding fields). Initial results from the survey reveal variations from only 1-6 coding fields available in some countries (Guatemala and Mauritius) to an unlimited number in other ones (Netherlands, Thailand and Iran). WHO recommends a large number of coding fields to accurately capture patients' information. With few coding fields, it is expected that co-morbidities, such as chronic conditions, will be underreported. The selective underreporting of diagnoses and procedures affects the sensitivity of coding, and could thus bias outcomes and risk models [11].

Definition of "main condition": Disparities also exist in the definition of "main condition". Only 40% of surveyed countries use the recommended definition from the WHO: "resource use" — most

Figure 1: Role of Coding Specialists within the Data Management Chain (orange).

responsible diagnosis for the patient's stay in hospital. If admission data describes multiple conditions, this is defined as the diagnosis that is most responsible for the longest portion of the length of stay or greatest use of resources. The remaining 60% utilize "reason for admission" — the condition established after study to be chiefly responsible for causing the admission of the patient to the hospital for care. These varying definitions of main condition could present challenges when comparing healthcare data internationally [10].

Mandatory data fields: The mandatory data fields in the hospital morbidity database differ among the surveyed countries. For example, mandatory data fields included: patient demographics, information about admission type or discharge disposition, admission unit, and diagnoses. Diagnosis timing and physician information were least frequently required in the countries we surveyed.

3 Training of coding specialists

In the countries that employ dedicated personnel for assigning ICD codes, their training vary in length and type. In these countries, they are referred to as coding specialist, clinical coders or health information managers. Interestingly, Germany and Italy do not train or employ coders, but instead use physicians or statisticians, like in Paraguay and Guatemala.

Training requirements: Some countries don't mandate any training qualifications (e.g., Sweden, Netherlands, Chile or Thailand), but in those who do, college/university degree is the most common requirement. In Canada and Australia, for instance, it is mandatory for future coding specialists to complete a 4-year college-level program and pass a national certification exam. Conversely, United Kingdom has 1 to 2 years-long course certificates, New Zealand offers 1 month to 1 year-long coding courses, while Uruguay only offers on-the-job training. Accordingly, type and duration of training could range from an on-the-job training shorter than 1 month, to a college-level program greater than 2 years.

Training opportunities and resources: As a result of the continuous improvements in ICD, and especially in preparation for the transition to new versions, general education and awareness, as well as specific coding training curriculums need to be developed and provided to keep coding specialists up to date. Continuing education (i.e. ongoing education after initial formal training or certification) for clinical coders is offered in most countries except for Nigeria, Tanzania and Chile, according to survey results. Additionally, the countries have varied resources available for assisting coders, such as ICD coding books, software, standards, and phone support.

4 Challenges and opportunities

As we have discussed above, different countries use the ICD system differently. While the WHO has published ICD-11 which might solve some of the issues, it is expected that many countries will continue using ICD-10 long into the next decade. Thus, we are likely to still need to compare data coded in ICD-10 with country variations, as well as potentially compare across ICD-10 and ICD-11. Similarly, differences in training are unlikely to disappear. Given this landscape, how do we support comparisons?

When morbidity-data coding differ between countries, can we still compare their data, and if so, then under which circumstances? We explore two challenges and opportunities in the following.

Different level of detail: With different levels of detail between countries, it is likely that some things cannot be compared easily. Above, we suggested that co-morbidities, such as chronic conditions, might be underreported in countries with fewer diagnosis coding fields. We suggest uncertainty visualization might play a role in helping to compare these. Additionally, we might consider providing data beyond aggregate summaries for different countries thus surfacing the concrete differences in visualizations.

As a first step towards addressing this challenge, we might use data from a specific country, and then create visualizations of this data with the perspective of data collection in other countries in our survey. For example, we could use a high-quality dataset of Canadian hypertension cases. Using our knowledge from the survey, we might simulate different countries by limiting the amount of coding fields. We can then create a visualization of these simulations to communicate the potential impact of varying data quality.

Different training: With varying or perhaps contrasting training differences, leading to different skills sets for the people coding medical charts, we risk differences in how a clinical event is coded between countries. In addition to differences in level of detail, different coders might code semantically differently, that is, we would expect a low inter-rater agreement. Further, we expect these differences to be exacerbated between countries.

Knowledge from our survey might be used to group countries with comparable training programs together, for example in small multiples or similarly, to utilise a visual variable for communicating these different groups of countries. Beyond this, we consider this to be an unsolved problem and question whether and how visualization might play a role in working towards a solution to this issue.

5 Conclusion

Variability in the features of the data collection system as well as the coders' training leads to baseline differences in coding practices across countries. Our online survey, which is briefly introduced here, aimed to characterize ICD use and training internationally. Ultimately, the knowledge generated from this survey will be valuable to the WHO for the promotion of ICD and the rollout of ICD-11. Additionally, it might improve comparisons of healthcare data globally, and encourage further research on how to improve ICD coding.

References

[1] S. M. Cadarette and L. Wong. An introduction to health care administrative data. *The Canadian Journal of Hospital Pharmacy*, 68(3):232, 2015.

[2] R. Charon. At the membranes of care: stories in narrative medicine. *Academic Medicine*, 87(3):342, 2012.

[3] M. Correll. Ethical dimensions of visualization research. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, p. 188. ACM, 2019.

[4] K. Doyle and V. Dimitropoulos. Keeping our classification up to date. *Health Information Management Journal*, 38(1):50–52, 2009.

[5] J. Drucker. Humanities approaches to graphical display. *Digital Humanities Quarterly*, 5(1):1–21, 2011.

[6] A. Hinds, L. M. Lix, M. Smith, H. Quan, and C. Sanmartin. Quality of administrative health databases in canada: a scoping review. *Canadian Journal of Public Health*, 107(1):e56–e61, 2016.

[7] N. McCurdy, J. Gerdes, and M. Meyer. A framework for externalizing implicit error using visualization. *IEEE transactions on visualization and computer graphics*, 25(1):925–935, 2018.

[8] N. H. Møller and P. Bjørn. Layers in sorting practices: Sorting out patients with potential cancer. *Computer Supported Cooperative Work (CSCW)*, 20(3):123–153, 2011.

[9] W. Paoin, M. Yuenyongsuwan, Y. Yokobori, H. Endo, and S. Kim. Development of the icd-10 simplified version and field test. *Health Information Management Journal*, 47(2):77–84, 2018.

[10] H. Quan, L. Moskal, A. Forster, S. Brien, R. Walker, P. S. Romano, V. Sundararajan, B. Burnand, G. Henriksson, O. Steinum, et al. International variation in the definition of 'main condition'in icd-coded health data. *International Journal for Quality in Health Care*, 26(5):511–515, 2014.

[11] P. S. Romano and D. H. Mark. Bias in the coding of hospital discharge data and its implications for quality assessment. *Medical Care*, 32(1):81–90, 1994.

[12] World Health Organization. ICD-11 Reference Guide. `https://icd.who.int/icd11refguide/en/index.html`. Accessed: 2019-06-14.

[13] World Health Organization. ICD Classifications. `https://www.who.int/classifications/icd/en/`. Accessed: 2019-05-25.