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Data Maps and Mapping – The Unseen Bomb !

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Abstract. Data maps to translate information recorded in one code system to another code system are common in digital health. In the past these were used for data aggregation and national reporting where minor errors caused little impact. Today these maps are used invisibly behind the scenes when sharing clinical data. This is a data quality and safety bomb ready to blow. The International Standards Organization (ISO) have prepared to review their standard on map quality, a standard which when used can identify safety and quality issues in mapped data and assist in development of a pathway to improvement. The key determinants of map quality are discussed here and their impact on patient safety considered based upon real world experiences. Suggestions are included on the potential minimal requirements for any map used in a clinical environment, whether for use for interoperability or for other purposes. Alternatives to encourage improvement in map quality are also suggested.

Keywords. Data quality, data management, health information interoperability

1. Introduction

Data maps are being included increasingly in healthcare systems. These maps have generated issues of patient safety and data usability and are also expensive to create and maintain. The International Standards Organization (ISO)'s international experts have developed measures of map quality intended to be used to verify that the map is safe for use. This paper discusses the measures of data quality identified in the standard and their impact on data quality – ISO/TS 21564:2019 Terminology Resource map Quality Measures (MapQual) [1]. This paper aims to develop a broader understanding of the need for improved governance of data maps used in healthcare systems. This work goes on to suggest potential extensions to this standard when it comes up for review at ISO in the near future. This reports learnings from the use of this standard to evaluate maps created by a range of digital health projects over the last 3 years[2].

This standard offers a way to ensure the quality and safety of mapped data. Historically mapping was mostly used for aggregation of reportable data i.e., from local data to national data collection. Where the map does not provide a one-to-one equivalence, this may not impact the usability of the map for reporting or administrative purpose, but when used for clinical purposes the result can affect patient safety and the ability of the treating clinician to provide appropriate care.

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This international standard supports independent assessment of the quality, safety, and utility of maps. Today maps are used in many software products for patient care, including for information exchange where such a quality assessment has not been done. HL7 FHIR have developed a specification for data map content which recognizes the input of the ISO MapQual requirements [2], but the requirement for assessment has had limited take up. This is largely due to lack of knowledge about the standard. Where independent assessments have been undertaken the maps can be used with increased confidence, software vendors can be encouraged to move to standardized data representations to reduce the use of local code systems which require maps. Thus, reducing the costs of mapping and improving the quality of data.

2. Methods

This research uses the ISO standard [1] reviews and provides examples of how it supports map quality evaluation. The ISO process takes input from national experts in confidence to establish the best practice approach to a task, in this instance data mapping. The document is then reviewed by the national committees of each member country and updated to reflect their input. The ISO process provides results that formal research often cannot because of privacy and political implications.

3. Results

The determinants of map quality were reviewed in 4 main areas, terminological resource capacity, and equivalence of individual maps, building a map set and map governance and maintenance. Inconsistent use of terms was identified at ISO – the standard uses these terms consistently. For example: mapping is a verb not the result of a mapping process. Throughout this work maps are the artifact. Most maps include multiple codes from one code system and the rules by which they are converted to an alternative code system. Each individual map converts from a single source code (from the original code system) to the code in the target (result) code system, while a group of such instructions is a map set [3].

3.1. Terminological resource capacity

The terminological resource capacity considers whether the source and target maps have a similar scope, structure and language. This quality determinant identifies whether attempting a map between these concepts will be useful or produce an outcome that meets the intended use case. It is often difficult or impossible to produce a useful map between code systems with structures that are not covering the same scope or viewing the content from different perspectives. Example of poor quality: A map was requested between fiscal codes for inpatient services to be mapped to outpatient services – these services have very different scopes – there is limited overlap and therefore producing a map from one code system to another is unlikely to produce a useful outcome. What was needed was a new joint classification covering the total scope and then each of the original code systems could have been mapped to that new code

3.2. Equivalence of individual maps

Equivalence determinants include the need to:

- publish the equivalence of individual maps to support user assessment of the data provided,
- assess the equivalence of each individual map and the map set more generally.
- understand outliers that do not fit the requirement for equivalence and how this is determined.

Whether the source and target codes in a map have the same meaning must be known when interpreting the data. For example, a clinician who is presented with data that is less specific than it was in the original patient record should be aware of this. The Standard gives measures of equivalence, as well as what is needed in the published map to allow the user of the mapped data to assess the quality of what they receive. Guidelines are provided on map set outliers. This is where the impact of different levels of equivalence in the whole map set is evaluated. How much variation is acceptable for the use case?

Equivalence can be assessed based upon meaning and on lexical (linguistic) representations. For example, if the equivalence has no meaning change, the work is safe for clinical use but if the meaning has become less specific this might be determined as safe but not ideal for use, provided that this problem only occurs in conditions which will not impact care planning or where the variation only impacts say 5% of the episodes. The decision on equivalence need is based on the use case and potential safety impact.

3.3. Building a map set

The creation of a map set includes clear statement of the purpose of the map. When there are alternative options for the target (result) code the decision is based upon the way the map is intended to be used. The only maps which suit multiple use cases are those with 100% semantic equivalence of all individual maps in the map set. Such maps are rare.

The currency of the map is a major factor. This requires consideration of the frequency of changes to the source and target code systems. When either change, the map may need to change. The map building process must take this into account.

Business arrangements where third parties are employed to create a map need to be evaluated to define what was required of the service provider and to mitigate risk of vested interest/s of that service provider.

The methodology for map development needs to be planned and documented clearly. Without this, different people working on the map may approach and make decisions differently resulting in inconsistencies, or the validation process may not be clear or part of the requirement for implementation.

Validation processes and any tools used need to be repeatable and known. For example, How much of the map will be validated? There was a case where a map of pharmaceutical products was created and only 5% of the content was validated. This was a map used in clinical practice – and nearly resulted in harm to patients. There are many methods of validation and the method chosen needs to reflect the accuracy and risks associated with the use of the map.

Tools are used in many mapping projects. These can be very useful but need to be chosen considering the quality required of the end-product. Examples of common

tools include natural language processing, ontology management tools, terminology servers and management tools.

The workforce involved in map building is also an essential component of quality measurement. The team must include detailed and practical skills and knowledge of both code systems and any rules used which apply to these systems. Governance skills to ensure consistent and appropriate documentation are required as is input from the user community of both source data and target data. Key participants are the decision maker or sponsor, the project leader, the map specialist (code system specialist), map implementer, map governance team members. The Standard provides a detailed skill matrix indicating the level of skill in a wide range of areas to assist in evaluation and establishment of the team.

3.4. Maintenance and Governance

Before moving into an environment which uses data maps it is important to understand if the map is for one off use – to translate data from an older collection code system to a new one, in which case requirements for long term management are not going to be as important, but quality is still a major issue. If the map is to be used ongoing, such as those used when sharing information between different systems, ongoing governance, quality assurance, and retention of skills and consistency is essential. The cost and quality of a map is influenced by the frequency of code system updates for each code system as when either the source or target code system are modified (or the rules which govern their use are modified) the map must be updated as well and go through quality assurance techniques based upon the extent of the change.

4. Discussion

Maps are an essential requirement in a complex digital healthcare system where the data supply chain is both broad and deep. The requirements for maps used in clinical practice, including those used to build messages between software implementations and different care environments, need to meet the following key quality metrics:

- Source and Target scope are compatible, for example the target may be broader than the source but not less than the source, unless the use case is also limited
- Source and Target structure are consistent, where there are different levels of granularity these levels need to be clear to those receiving the data.
- Equivalence must be one to one in order to ensure semantic interoperability
- The development process must be well documented and the rationale behind all decisions must be consistent and clear and applied throughout the map (otherwise the resultant map is not consistent and potentially unsafe)
- The team must have the skills needed across all roles in the map project
- Governance and maintenance must be planned, and the plan adhered to
- Independent assessment of the map quality should be undertaken regularly (based upon the frequency of changes to the source and target code systems).

These requirements impact healthcare. Maps have been used as a common tool to solve the lack of a common data infrastructure, using the point of an information message and a data map to move to standardized concept representation. The introduction of data standards used in conjunction with terminology standards is a good step in this direction,

but software vendors need to be encouraged to change their existing approaches. They can be encouraged if they see an improved opportunity to plug and play which offers a greater market for their product. The other option uses a 'stick'. If vendors provide the maps they use – they can be required to provide independent evaluation of map quality, showing that their map and mapping process meets the minimum safety requirements for the use case in which they are employed. These approaches together can reduce the change over time.

Increasingly the ISO TC215 Health Informatics community is producing standards to assist in quality assessment. Such standards include how to measure the quality of your terminology implementation – a current work item on the Working Group 3 Semantic Content work plan. Too often healthcare thinks only of standards for messaging, but there are many other elements to quality practice and efficient safe systems. Another issue is that some excellent options are not well known and less well used. The standard discussed here is an example of such a piece of work.

5. Conclusions

All decision makers, developers, and health informaticians need to be aware of standards developed by the members of the Joint Initiative Council of Health Informatics Standards Bodies (JIC). These are developed by world experts and can significantly reduce overheads and reduce risks in system development and implementation. The MapQual standard is just one example of this type of publication.

Maps are vital parts of digital health but must be used with knowledge and developed with skill. The maps used in the past for national data capture may have introduced minor discrepancies which may not have caused significant harm. That world is gone! As healthcare becomes more digital the potential impact of the innocuous mapping tool is not well understood or treated with the respect needed to protect patients and reduce costs. It is time to consider our options and leverage the resources that can help our systems do it better before the bomb blows up!

Acknowledgements

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