Caring is Sharing – Exploiting the Value in Data for Health and Innovation
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Standardization Proposal for the Transmission of Waiting List Data in Italy

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Abstract. Each Italian region is required to manage and disclose data relating to waiting times for healthcare services which are provided by both public and private hospitals and local health units accredited to the *Sistema Sanitario Nazionale* (SSN – in English, National Healthcare System). The current law governing data relating to waiting times and their sharing is the *Piano Nazionale di Governo delle Liste di Attesa* (PNGLA – in English National Government Plan for Waiting Lists). However, this plan does not propose a standard to monitor such data, but only provides a few guidelines that the Italian regions are required to follow. The lack of a specific technical standard for managing sharing of waiting list data and the lack of precise and binding information in the PNGLA make the management and transmission of such data problematic, reducing the interoperability necessary to have an effective and efficient monitoring of the phenomenon. The proposal for a new standard for the transmission of waiting list data derives from these shortcomings. This proposed standard promotes greater interoperability, is easy to create with an implementation guide, and has sufficient degrees of freedom to assist the document author.

Keywords. Waiting list data, interoperability, standard

1. Introduction

Monitoring waiting list data in healthcare has great relevance in ensuring all citizens have access to health services that are insured and adequate for the clinical problems presented. One of the main tasks of the *Servizio Sanitario Nazionale (SSN* – in English, National Healthcare System*)* concerns with meeting citizens' healthcare needs and providing transparency regarding waiting times. As a matter of fact, public and private bodies, that provide health care on behalf of the SSN, are required to show on their website both the expected waiting times and the actual average waiting times for each type of service provided [1]. Currently, the waiting lists and waiting times issues are governed by the

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Piano Nazionale di Governo delle Liste di Attesa (PNGLA – in English National Government Plan for Waiting Lists*)*, which is a plan designed to guarantee citizens fair, appropriate, and timely access to health services limiting access times [2], even though often last longer than necessary [3]. The current edition of the plan straddles the pre-COVID-19 and post-COVID-19 period; therefore, if under ordinary conditions waiting times may not be respected, during the COVID-19 emergency this problem is even more exasperated and both waiting times and waiting lists have been further extended. For example, the Organisation for Economic Co-operation and Development (OECD), which offers extensive data on this topic, states that during the pandemic, patients' time on waiting lists for several services increased [4]. Moreover, the OECD recognizes that it is difficult to find common definitions of criteria to detect waiting lists [5]. Indeed, waiting list data's major problem is that waitlist statistics not only remain fragmented and difficult to compare across countries, but in Italy, they even are incomparable among different regions. Italian healthcare is organized at a regional level, and in accordance with the law, regions should publish waiting list data to make healthcare public administration data, documents, and information available [6], but this requirement is not always satisfied. In February 2021, The Bridge Foundation started a project focused on the 2019 and 2020 waiting list data collection and comparison [7]. During this two-year analysis, heterogeneity was found in the data provided by the regions, and moreover, a change in the method of collecting information from one year to the next was also observed. The current version of PNGLA obliges NHS-accredited health units and hospitals that provide health services to disclose information regarding waiting lists, but this plan contains too many degrees of freedom: there are not enough indications to ensure that all regions can present homogenous datasets. Therefore, this work does not aim to find a solution to long waiting times in healthcare but to improve the management and sharing of waiting lists.

2. Materials and Methods

To allow the development of an efficient and effective tool for monitoring and sharing data regarding waiting times in healthcare, particular attention was paid to the PNGLA. The plan identifies a list of healthcare services, that are subject to controls on waiting times, divided into outpatient services and hospitalization services and, in turn, outpatient services are divided into specialist visits and instrumental performances. The plan also establishes the maximum times within which they must necessarily be provided, depending on the priority assigned at prescription time. Therefore, patients considered more serious are subject to shorter waiting times, compared to less urgent cases. In the specific case of outpatient services, priorities U, B, D, and P are used (in decreasing order of urgency), while for hospitalizations, classes A, B, C, and D are used (in decreasing order of urgency). Considering these guidelines, a standardization method for the management and sharing of waiting list data is therefore proposed to foster interoperability, a mandatory requirement stated in Italian law [8]. Finding a proper document structure for the creation of the new standard was not easy. An Italian law of 2015 [9] requires the adoption of HL7 Clinical Document Architecture (CDA) for all documents to be recorded in the Regional Health Informatic Infrastructures. Therefore, the authors decided to take a cue from the CDA to design a new draft standard document also following the suggestion of some colleagues of *Liguria Digitale* (the informatic public company of Liguria Region). These colleagues also provided us with raw data to

be able to carry out tests, , specifically designed to monitor and share data regarding waiting times for healthcare services. As the CDA is an Extensible Markup Language (XML) based markup standard, we decided to create a new document based on XML. To create the structure of the document we used the Integrated Development Environment (IDE) Visual Studio Code. After implementing the general structure of the XML document, containing everything necessary for the correct monitoring of data regarding waiting times in healthcare, we created an XML Schema Definition (XSD) to validate the document, again using Visual Studio Code as IDE. Since the raw data provided by *Liguria Digitale* were in XLSX format, we designed a program that allows the conversion of this file into a document in XML format. To build this program, we used Python Programming Language, using PyCharm as IDE.

3. Results

Therefore, for the sharing of waiting list data, we created a new draft standard, the Waitlist Document Architecture (WDA). Taking a cue from the CDA, also the WDA document consists of two major sections: the WDA header and the WDA body. The header identifies the document type and provides information on the figures involved, such as the region (Figure 1), the author and the custodian of the document, and the period (Figure 2), which contains information about the year and the month or quarter to which the collected data refers. To uniquely identify the figures involved, specific, already existing codes must be used. For example, to identify the regions, the statistical code of territorial administrative units (provided by the Italian Institute of Statistics - ISTAT) must be used, while to identify the author and the custodian of the document, the tax code must be used.

```
<recordTarget>
    <regionRole>
        <id code="070" codeSystemName="ISTAT" assigningAuthorityName="Liguria"/>
        <region>
            <name>Liguria</name>
        </region>
    </regionRole>
</recordTarget>
```

Figure 1. Region coding example.

```
<period>
    <year>2020</year>
    <month>02</month>
</period>
```

Figure 2. Period coding example.

The body is a structured XML body, which contains information regarding the healthcare services, relative values on waiting times, and the health facility that provided these services. We designed two different WDA documents, according to the type of monitoring. For outpatient services, it is possible to insert two specialty sections, one concerning specialist visits and the other concerning instrumental performance. Instead,

for hospitalizations, it is possible to insert a single specialty section, concerning only hospitalization services. We decided for this option to consider the already existing different nomenclatures of healthcare services. Indeed, specialist visits and instrumental services are coded in compliance with *Livelli Essenziali di Assistenza (LEA* – in English Essential Assistance Levels) codes, while hospitalizations are identified according to the International Classification of Diseases, 9th revision, Clinical Modification (ICD-9-CM) codes (Figure 3).

```
<component>
    <section code="89.7A.3" codeSystemName="LEA" displayName="Prima Visita cardiologica">
        <title>PRIMA VISITA CARDIOLOGICA</title>
```

Figure 3. Example of use of the terminology of healthcare services.

Accordingly, each specialty section must contain several "leaf" sections, containing the name of the service and the corresponding LEA code or ICD-9-CM code. For each region, each healthcare service can be provided by several health institutions or facilities. Therefore, within each "leaf" section there is a CLUSTER-type organizer tag, which can be replicated for each type of structure and/or facility present, and each facility or structure is associated with a unique identification code. Both the monitoring of waiting times for outpatient services and for hospitalization services require the inclusion of the priority class of the service in question. Therefore, for each structure or facility, it is possible to enter several observations of the same service associated with a specific priority class (Figure 4). Although the use of priority classes is mandatory, it often happens that it is not specified. For this reason, we decided to insert a generic observation, which does not specify the type of priority of the healthcare service in question. If the priorities associated with the service in question are managed, the observations must be completed with one of the codes of the HL7 ActPriority dictionary, characterized by its own Object Identifier (OID).

```
<priorityCode code="A" codeSystem="2.16.840.1.113883.5.7"
codeSystemName="Act Priority" displayName="ASAP">
    <translation code="B" codeSystem="2.16.840.1.113883.2.9.5.2.3"
    codeSystemName="Priorità Visita" displayName="Breve"/>
</priorityCode>
```

Figure 4. Example of using priority classes.

Finally, for each observation, there must be at least one of the number of reservations guaranteed on schedule according to the type of priority (if any), or the ratio between the number of reservations guaranteed on schedule, compared to the total number of reservations (guarantee percentage). Optionally, the total number of reservations in the month or in the quarter in question can be added (Figure 5).

```
<values>
    <totalNumber>143</totalNumber>
    <mean>136</mean>
    <percentage>95,10</percentage>
</values>
```

Figure 5. Example observation values.

Then, the validation of the WDA document makes it possible to verify if all the mandatory information is present, and if the data entered is correct. Furthermore, to help the author of the document write a WDA document, we created an Implementation Guide, containing the instructions necessary to write both the header and the body of the document.

4. Discussion and Conclusion

This project is currently still under development to try to make further improvements to facilitate the use of this standard. However, simulations have already been carried out with already-acquired data, provided by *Liguria Digitale*. Converting the data into XML format, allows us to implement more in-depth checks on the quality of the data itself, allowing us to have information that is not only available but also usable. This proves the validity of the project and that it is legitimate to assume that we can continue with further analysis and investigations. This proposal is based on the present PNGLA relating to 2019-2021, since at the time of writing this article, the version of the plan for the 2022-2024 period is not yet available. Therefore, for the next few years, the authors expect greater standardization also on the part of guidelines to ensure greater interoperability and constant monitoring and transmission of data. A further aim is to propose the WDA document as a new standard for transmitting waiting list data to HL7 Italy to create a turning point in the future of this topic. At present, this document is intended to represent only the structure of a possible new data-sharing standard but implementing a FHIR profile with APIs in the future could be a significant evolution in terms of easier implementation. Another possible evolution could be also the adoption of a terminology management system to consider future versions of applied terminology [10]. Moreover, we are looking for enthusiastic young people who are willing to learn how to implement our standard and bring innovative ideas that can help the development of this proposal.

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