Pilot Study for a Model for the Collection of Waiting Lists Data

Rosaria IARDINO[a], Elisa SALA[b1], Emanuela REALE[c], Luisa BROGONZOLI[a], Monica BONETTO[d], Alessandro VENTURI [b, e], Mauro GIACOMINI[f], Maria Pia RANDAZZO[c]

[a] *Fondazione The Bridge, Milan, Italy*
[b] *Department of Political and Social Sciences, University of Pavia, Pavia, Italy*
[c] *Health statistics and information flows unit, National Agency for Regional Healthcare Services (AGENAS), Rome, Italy*
[d] *Healthropy s.r.l., Savona, Italy*
[e] *I.R.C.C.S. Policlinico San Matteo, Pavia, Italy*
[f] *Department of Informatics, Bioengineering, Robotics and System Engineering, University of Genoa, Genoa, Italy*

ORCiD ID:
Rosaria Iardino 0009-0003-8474-644X
Elisa Sala 0009-0006-1635-5692
Luisa Brogonzoli 0009-0004-0510-3559
Monica Bonetto 0000-0002-5317-1060
Mauro Giacomini 0000-0001-5646-2034

Abstract. The analysis of data on waiting lists in Italy is regulated by the PNGLA (National Plan for the Governance of Waiting Lists). However, the Plan does not specify the characteristics of the data to be returned by the Regions for the purposes of monitoring, with the result that it is frequently either in aggregate form, unreadable, or incomplete, and therefore cannot be analysed in any meaningful way.
Fondazione the Bridge and AGENAS, with the University of Genoa and the University of Pavia, conducted a pilot study on a methodological model for the collection of waiting lists data.
The model proved to be effective and replicable, also providing a more valuable opportunity to analyse waiting lists data.

Keywords. Waiting list data; public health; monitoring; analysis; standardization; model; programming

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[1] Corresponding Author: Elisa SALA, csfondazione@fondazionethebridge.it

1. Introduction

Waiting times constitute a fundamental factor in the provision of those services whose delivery is guaranteed by the essential levels of care ("Livelli Essenziali di Assistenza", LEA), crucial to deliver the appropriate care to all citizens. Waiting lists are a factor in the equity of access to health services and in patient satisfaction alike [1,2]. The necessity of monitoring and sharing waiting lists data has been translated into the obligation of transparency adopted by the National Plan for Waiting List Governance ("Piano Nazionale di Governo delle Liste di Attesa", PNGLA) 2019-2021[2], that governs the data relating to waiting lists across the different Regions.

The data collected according to PNGLA guidelines was the object of two studies conducted by the HI Observatory[3], together with the Universities of Genoa and Pavia, that covered the years 2019-2020 [3] and 2021 [4]. However, the analyses highlighted some issues related to the discretion granted by the PNGLA 19-21 in the collection of data and could not lead to significant conclusions.

In fact, the PNGLA 19-21 gave the Regions the possibility to choose between a variety of different methodologies for data collection and dissemination: for example Regions could choose between monitoring the provision of the services ex post or ex ante, between either percentages or raw numbers of the total services provided within the required time, throughout the entire year or during an index period, and so on. These differences hindered the interoperability of data, and made the comparisons difficult not only at the national level, but also at the local, and between the same Region across different years.

For these reasons and building on their previous research, Fondazione the Bridge and AGENAS (National Agency for Regional Health Services), with the support of the Universities of Genoa and Pavia, conducted a pilot study to develop a new model for the collection of waiting lists data, with the aim of finding a valid alternative to the discretionary nature of the current method.

This model aims to collect homogeneous and standardised data and make it available at the regional level, improving the quality of monitoring, also from a prognostic perspective, and thus supporting Regions and healthcare facilities alike in enhancing their organisational-management skills.

The present paper details the methodology of this pilot study.

2. Materials and methods

In the first studies of waiting list times by the HI Observatory, the requested data consisted of the records that the Regions already made available to comply with the PNGLA, which was solicited through the civic access procedure, that therefore was

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[2] Recently, a technical table was set up for the development and operational implementation of the National Plan for the Governance of Waiting Lists (PNGLA) 2024-26 (Director's Decree no. 44016 of 22/12/2023).

[3] The HI Observatory (Healthcare Insights) is an independent observatory on healthcare access created by Fondazione the Bridge in 2020. It is focused on monitoring access to the healthcare system and of making information relating to the National Health Service public and accessible. For more information: https://www.hiosservatorio.it/

subject to the limitations already mentioned. For more details on the methodology of these analyses, see Bonetto et al., 2022 [5].

After the decision to launch the pilot study, a working group was set up consisting of AGENAS, Fondazione The Bridge, with the support of the University of Genoa and the University of Pavia. The first decision taken was to ask for precise variables and not merely the data required by the PNGLA, and these variables were then constructed by the working group.

Participation in the trial was on a voluntary basis. The various local health authorities were contacted by means of an invitation letter to the pilot, which was followed by a meeting in which the purpose of the experiment and the commitment required once accepted were explained.

Data was requested in ex ante form, concerning all the specialist visits and diagnostic services already covered by the PNGLA (14 specialist visits and 55 diagnostic services). The participants were sent the form to be filled in excel format. The data collection period was set in the index week of 22-26 May 2023.

The data was then analysed with respect to both the actual waiting list times and the assessment of whether the pilot model was effective and replicable.

3. Results

The study involved 44 Local Health Authorities, 18 Hospital Facilities, 2 Research-based Hospitalization and Treatment Institutions and 1 National Institute for Elderly Care, belonging to 13 out of the 21 Italian Regions. The respondent facilities covered a population base equal to 37 % of the Italian patient population (22,093,599 patients out of 59,030,133).
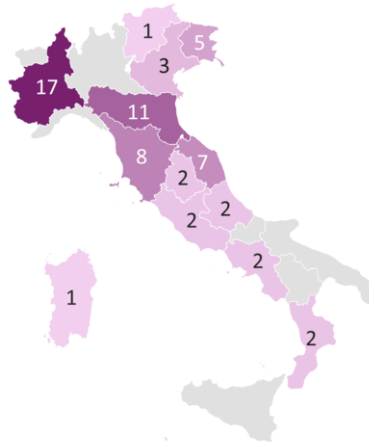
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Figure 1. Distribution of participating institution by Region.

The required data were analytical records on individual provisions (anonymised), coded in 27 variables, as shown in Table 1.

Variable name	Description	Value labels
Istat Residence	Istat code of the assisted person's Municipality of Residence	String variable
Municipality Residence	Name of the municipality of residence of the assisted person	String variable
Region code	Code of the booking region where the service will be provided	String variable
Region name	Name of the booking region where the service will be provided	String variable
Company code	Code of the Reservation Health Authority at which the service will be provided	String variable
Company name	Name of the Booking Agency at which the service will be provided	String variable
Structure code	Code of the facility where the service will be provided	String variable (STS11 code)
Structure name	Name of the Structure at which the service will be provided	String variable
Provider code (agenda code)	Code of the Booking Point (agenda) at which the service will be provided	String variable
Provider name (agenda name)	Name of the Booking Point (agenda) at which the service will be provided	String variable
Recipe	Prescription identification code	String variable
Progressive Code	Progressive number identifying the service	String variable
Service Code	Nomenclator code identifying the service	String variable
Discipline Code	Discipline code identifying the specialist visit	String variable, could be null
Service Description	Name of the service	String variable
Class Priority	Priority code reported in the prescription	U= within 72 hours; B= within 10 days; D= within 30 days (specialist visits), within 60 days (diagnostic services); P= within 120 days; N= not given
Access mode	If the service requested refers to a first access (or subsequent access)	1 = first access; 0 = subsequent access
Date of Prescription	Date on which the doctor prescribes the service	DD/MM/YYYY
Date of Contact	Date on which the citizen requesting the service comes into contact with the booking system	DD/MM/YYYY
Date of Prescription	Date assigned at the time of booking for the provision of the outpatient specialist service	DD/MM/YYYY
Date of First Availability	First date proposed by the booking system, taking into account the priority class and the territorial area of assistance and guarantee of the patient	DD/MM/YYYY
Facility Code First Availability	Provider where the first available date suggested by the booking system to the user at the time of contact/request	String variable (STS11 code)
Facility Name First Availability	Booking facility where the first available date is suggested at the time of contact/request	String variable
Provider Code (agenda code) First Availability	Provider point (agenda) where the first available date is suggested at the time of contact/request	String variable
Provider Name (agenda name) First Availability	Provider point (agenda) where the first available date is suggested at the time of contact/request	String variable
Number of services booked	Number of services booked	Number
User choice	User's choice of a date other than first availability	1= the user made no choice, i.e. chose the first availability offered by the system; 2= the user chose a date other than the first availability

Table 1. Variables collected in the pilot study.

Data on service bookings in the index week, from the 22nd to the 26th of May 2023, was provided via the single reservation points ("Centro Unico di Prenotazione", CUP).

The data was collected using the Excel template provided. The use of a univocal format made it possible to perform a homogeneous analysis of the variables. The results of the complete statistical analysis are not yet available.

4. Discussion

The first studies conducted on waiting lists by the HI Observatory had many limitations related to the quality of the data, which was in aggregate form and very often not interoperable, not homogeneous and not comparable.
Despite the fact that the pilot project had far fewer participants, as participation was on a voluntary basis, the quality of the data collected is significantly higher. The data collected is both comparable and intelligible and returns a true picture of the situation of waiting times in the Local Health Authorities from which the data was received. The quality of the data is improved because the format with which the template was provided is .xml, with well-defined and standardised variables, and is therefore interoperable and harmonised. The completeness of the data, in regard to those who were willing to participate, is also considerably higher than that of the PNGLA compliant data provided by the Regions, in whichever form they chose to collect and share it.

5. Conclusions

Despite the fact that after the first two analyses conducted a method of standardising the regional data was hypothesized by the researchers in order to improve the collection of data and the analysis of waiting lists [6], the method of monitoring had inherent limitations resulting from the data required by the PNGLA, and from the fact that the data was often times received in its aggregated form. The present experimental study proved to be effective and replicable, proving that if indicators are proposed, the resulting collected data is readable and comparable. The data must be requested in a specific format that allows it to be analysed, as it is interoperable and standardised. With adjustments concerning the addition of certain variables and the choice of whether or not to ask data to the single hospitals or to regional single reservation points (CUPs), which not all Regions rely on for collection, the proposed model could be extended at the national level, and be a useful tool for a reliable and complete collection of waiting lists data.

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