



Essential levels of health information in Europe: An action plan for a coherent and sustainable infrastructure



Fabrizio Carinci^{a,b,*}

^a EUBIROD Network, Hub for International health ReSearch (HIRS), Perugia, Italy

^b Serectrix snc, Pescara, Italy

ARTICLE INFO

Article history:

Received 6 August 2014

Received in revised form

22 November 2014

Accepted 23 November 2014

Keywords:

Health information

European Union

Cross-border data exchange

Privacy and Data Protection

ABSTRACT

The European Union needs a common health information infrastructure to support policy and governance on a routine basis. A stream of initiatives conducted in Europe during the last decade resulted into several success stories, but did not specify a unified framework that could be broadly implemented on a continental level.

The recent debate raised a potential controversy on the different roles and responsibilities of policy makers vs the public health community in the construction of such a pan-European health information system.

While institutional bodies shall clarify the statutory conditions under which such an endeavour is to be carried out, researchers should define a common framework for optimal cross-border information exchange.

This paper conceptualizes a general solution emerging from past experiences, introducing a governance structure and overarching framework that can be realized through four main action lines, underpinned by the key principle of “Essential Levels of Health Information” for Europe.

The proposed information model is amenable to be applied in a consistent manner at both national and EU level. If realized, the four action lines outlined here will allow developing a EU health information infrastructure that would effectively integrate best practices emerging from EU public health initiatives, including projects and joint actions carried out during the last ten years.

The proposed approach adds new content to the ongoing debate on the future activity of the European Commission in the area of health information.

© 2014 Elsevier Ireland Ltd. All rights reserved.

1. Introduction

Timely information is required to support health monitoring, research and governance in Europe.

During the last ten years, the European Union (EU) invested substantial resources to pave the way for a

common health information infrastructure through the second health programme (“Generate and disseminate health information and knowledge”) [1] and the FP7 research framework (“Optimising the delivery of health care to European citizens”) [2].

As a result, a stream of initiatives allowed translating seminal ideas into useful products, including analyses, policy recommendations, and working prototypes for the automatic production of specific indicators. After 14 years of continuous work (1998–2012), the action on European Community Health Indicators (ECHI) delivered an example

* Corresponding author at: Serectrix snc, Strada Vicinale Colle Cervone 40, 65125 Pescara, Italy. Tel.: +39 085 44 29 188; fax: +39 085 44 29 188. E-mail address: f.carinci@serectrix.eu

of implementation of a core set of public health indicators in Europe, concluding that “further efforts at DG SANCO and Eurostat are needed towards a permanent health monitoring system” [3].

Exploiting the results of more EU projects may help achieving this end. Specific work conducted by the EUROREACH project [4] recommended interfacing best practices from BIRO [5], EUBIROD [6], EUROHOPE [7] and SHARE [8] as a sustainable strategy for the continuous production of comparative indicators.

A common problem is that there is no mechanism in place to embed the above results in the European Statistical System (ESS) according to what has been envisaged by the ‘Regulation 1338/2008 on Community statistics on public health and health and safety at work’ [9]. The Regulation puts Eurostat in charge of providing adequate information for all EU Member States (MS). However, it does not indicate how the different areas therein specified may be efficiently covered [10], taking also into account other sector-specific monitoring systems managed by the European Centre for Disease Prevention and Control, the European Monitoring Centre for Drugs and Drug Addiction, and the European Environment Agency.

As a result, there is a high risk that successful achievements from previous projects would be not included in the information system that will be operated by Eurostat on a rolling basis.

An overarching framework is needed for public health monitoring in Europe.

To this end, a recent paper [11] urged the public health community to convince politicians to undertake concrete action on the roadmap agreed by the European Commission (EC), WHO and the OECD.

A relevant step was made in the reflection process on health systems leading to the Council Conclusions on 10 December 2013 [12], which invited the EC and MS to “cooperate with a view to establishing a sustainable and integrated EU health information system...exploring in particular the creation of a European health information research infrastructure consortium as a tool”.

These conclusions clearly attributed the identification of coherent solutions for health information in Europe as a joint responsibility of the public health community and national authorities.

The goal was tackled at meetings organized by DG-SANCO at EC premises, where representatives of EU-funded projects and MS involved in the Expert Group on Health Information (EGHI) were invited to discuss the contents of a “scoping paper” [13] finally delivered in 2014.

The document illustrated the potential benefits of a European Research Infrastructure Consortium on Health Information (ERIC-HI) as a springboard for the realization of a coherent EU health information infrastructure (EU-HII).

The primary aim of the ERIC-HI was to link individual researchers and networks in the area of public health and health systems through better information sharing and coordination.

Although based on a comprehensive vision, the scoping paper included an operational plan made up of many horizontal tasks derived from past projects (e.g. injury surveillance, disease registries, etc). Consequently, the

document missed the opportunity of identifying an overarching framework where all activities and different methods could be vertically integrated.

This result clearly showed that while MS request precise objectives and a solid sustainable infrastructure, public health leaders generally prefer maintaining their own networks, and fulfil separate tasks in relative isolation, rather than identifying interoperable solutions that would require potential mergers of different projects.

This way, it will never be possible to gain added value through an expanded collaboration in the following areas:

- efficient use of modern information technology (by engaging specialized professionals as peer designers of advanced solutions)
- legislative boundaries (privacy and data protection issues to guide the design of the system)
- practical gains of international collaboration (consultation with different types of users as a key to evaluate the practical advantages of a EU-HII)

So, what can the different actors do to help responding to the challenge of health information in Europe?

The EGHI meetings highlighted the need for MS and researchers to focus on the following aspects:

- agree common objectives
- define their precise roles and responsibilities
- fix the scale of the effort and source of funding

In this paper, we aim to provide the public health community with key action lines to deliver the following:

- a comprehensive vision to harmonize societal goals with technical and legislative issues in the cross-border exchange of health information in Europe

The following sections will propose a general framework and introduce the “Essential Levels of Health Information” (ELHI) as a key concept for implementing this vision.

2. A new governance model for health information in Europe

The production of many indicators requires using multiple sources and data elements, in order to apply advanced techniques e.g. multivariate risk adjustment, in a unified manner across Europe.

The Regulation 1338/2008 requested MS to collect and transmit micro and aggregated data, in compliance with high quality criteria, standard metadata specifications, and data protection principles laid down in Directive 95/46/EC [14].

However, the content of the Eurostat portal six years after its approval [10] still lacks the expected degree of “greater accuracy and reliability, coherence and comparability, coverage, timeliness and punctuality” [9].

To fulfil these tasks, the information infrastructure of MS needs to be substantially strengthened.

Download English Version:

<https://daneshyari.com/en/article/6239382>

Download Persian Version:

<https://daneshyari.com/article/6239382>

[Daneshyari.com](https://daneshyari.com)