



# An empirical study of healthcare providers and patients' perceptions of electronic health records



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## ABSTRACT

This paper is the result of a legal and policy analysis of a statistical poll focused on the area of Livorno conducted by the LIDER-Lab of the Scuola Superiore Sant'Anna (Pisa, Italy). Information were gathered by submitting questionnaires to both healthcare providers and their patients. The scope was to evaluate the interest engendered by the application of technology on health data processing along with the needs, expectations and concerns of patients and healthcare providers. The paper leads to the main policy proposals of increasing financial investments in e-health (or at least preserve this area from the generalized budget constraints public health is suffering nowadays) and introducing incentives to use computers for general practitioners.

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## 1. Introduction

Electronic Health Record (EHR) systems are one of the most important Information and Communication Technology (ICT) based solutions for the healthcare sector. They represent a new form of communication and management of patients' health data. The so-called EU Article 29 Working Group defines an EHR as follows: "a comprehensive medical record or similar documentation of the past and present physical and mental state of health of an individual in electronic form and providing for ready availability of these data for medical treatment and other closely related purposes" [2]. ICT allows for the accumulation, in a single electronic document, of all the health data of a person in order to improve their access and use by authorised individuals and third parties when required. Such an improvement is better understood considering how EHRs differ from traditional documentation on medical treatment and health data. Traditional medical records, created and stored by health care providers or organisations, are restricted to certain types of data in function of medical specializations and the actual service provided. Furthermore, they do not allow a global vision of the patient's health conditions. An EHR, instead, aims to gather health data, potentially generated by different sources at different times, and to share those data with relevant healthcare actors.

EHR is also different from Personal Health Records (PHR) [15,23,25], another application of ICT in the field of health data management. The distinction is stressed by the term "personal". While an EHR is maintained by health professionals and official agencies, PHR is a collection of health-related information documented and maintained by the individual to whom they pertain (data subject), using the service offered by a provider. The most famous PHR is *Microsoft HealthVault*,<sup>1</sup> available in the US and in the UK, which aims to empower the data subjects to better manage their medical data. The patient can manage PHR with no third party intervention on the records. She directly enters on the PHR health data such as blood type, blood pressure, vaccinations, drugs used and previous diseases. The accuracy of such medical data is her responsibility. The patient can decide to never share her PHR, or to share it with her relatives and/or her physicians via online health services.

It is important to notice that in Italy, PHR is not diffused. However, Italian public authorities are developing systems of EHR in order to take advantages of interoperable databases of medical data. The main benefit anticipated by the digitalisation of medical records is better coordination of treatments. EHRs enhance the quality of care allowing speedy access to the comprehensive medical history of patients. In addition, health data ubiquity can reduce potential duplication of medical tests and errors caused by poor circulation of information [3,21]. In addition to this, public authorities expect that EHRs will help to provide faster and more efficient health services to citizens and to

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<sup>1</sup> It is significant to note that Google decided to discontinue its PHR, *Google Health*, for commercial reasons from 1st January of 2012 (see [www.google.com/health](http://www.google.com/health)).

reduce the costs of healthcare systems [12,22,27]. Finally, greater control of health data can enhance a patient's awareness about her own state of health [1,26].

The expectation since the late 1990s has been that EHRs ought to be integrated, on the basis of the multiple advantages they offer, into most healthcare systems [5,11,14]. The European Union, in proposing a strategic plan concerning ICT adoption in the healthcare sector,<sup>2</sup> has begun promoting the creation of EHR systems in all Member States. The first step in this process was the implementation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare. It purported that personal health data should be able to flow from one Member State to another so as to ensure continuity of care.<sup>3</sup> In the article dedicated to eHealth, the EU articulates its support for coordination between Member States in creating an "E-Health network".<sup>4</sup>

Against this backdrop, the present study has the more limited scope of illustrating the impact of the application of digital technologies to the healthcare sector exploring two specific issues. On the one hand and as a preliminary step, it investigates the actual level of knowledge of patients and general practitioners on the topic of computer applications to the processing of health data. On the other hand, it focuses on the needs, expectations and concerns of patients and professionals, at least as these two groups perceive them. Although its scope is more limited the study concludes calling for further analysis on the impact PHRs and EHRs can have on the standard of care in medical liability and for the providers of technologies and services related to the use of EHR (e.g. Internet service providers, software engineers, etc.).

In particular, bearing the international background of e-Health in mind, our focus has been to investigate the actual perception of EHRs by professionals and patients in a small, defined geographical area. For this reason, we chose Livorno, a medium sized Tuscan city of approx. 160,000 inhabitants, as a suitable area for the dissemination of a questionnaire specifically drafted for the poll. These questionnaires were submitted to both general practitioners and their patients. The general scope of this empirical experiment was to evaluate the awareness of EHRs and determine the demands, expectations and fears of both categories of health actors. Although the questionnaire and the interview questions were not drawn up with a specific catchment area in mind, we cannot automatically claim that analogous results would be found in other local or national contexts because several social and demographic variables could influence some results. Yet, if we project the results found at the national level or at comparable catchment area, we consider that our research stresses interesting issues for a larger debate among health actors and policy-makers concerning the generalisation of technological application in the healthcare sector. Analytical results will be further discussed in Sections 4–8 after having briefly described the Italian normative background in Section 2 and the empirical study methodology in Section 3. To avoid excessive length of the article, tables refer to what we think are the most interesting data resulting from the questionnaire. Finally, Section 9 focuses on policy and legal analysis stressing the need for further research on the impact HER can have on professional and ISP providers liability.

## 2. The legal background to electronic health records in Italy

In Italy, the State, Regions and local authorities share competence on healthcare. According to article 117 of the Italian Constitution, the

introduction of EHRs is a competence belonging to the Regions. Nevertheless, at the national level, the Innovation and Technology Department and the Health Department created a special committee comprised of representatives from all Regions to investigate the prospects of harmonized digitalisation of the health sector.

Recently, a definition of "*Fascicolo Sanitario Elettronico*" (EHR) was introduced by Article 12 of the Decree 18 October 2012 no. 179, establishing the scope, the controllers and the recipients of health data processing.<sup>5</sup>

Anticipating this legislative definition, the Italian Data Protection Authority in 2009 established guidelines on EHRs aimed at protecting citizens' privacy [9]. These privacy guidelines were recently further bolstered by national Guidelines on EHRs by the Health Department.

At the moment, the Italian infrastructure of EHRs is based on the federation of the regional architectures established in Italian regions which is called to guarantee the localisation and management of patient health data. Communication among the regional systems is then permitted via the "*sistema pubblico di connettività*", a public infrastructure. While some regional systems are quite well developed (for example, Lombardy,<sup>6</sup> Emilia-Romagna<sup>7</sup> and Tuscany<sup>8</sup>) the interconnectivity of EHRs is not yet a reality at national level, revealing that the Italian system is running behind in dealing with these issues and signalling even lack of awareness of potentialities and concerns in electronic health records as our research illustrates.

## 3. Research methodology

Indeed, the hypothesis sustaining our research is that one of the most important difficulties in the implementation of EHRs in Italy is the capability of patients and physicians to adopt health data innovation.

In order to understand the perception of health actors when faced with EHRs, the Lider-Lab of the Scuola Superiore Sant'Anna, Pisa ([www.lider-lab.org](http://www.lider-lab.org)), with the help of the Italian Medical Association, of the General Practitioners Association of Livorno and the financial support of the "Cassa di Risparmio di Livorno Foundation", redacted and submitted two different questionnaires: one for patients and another for general practitioners. We decided to execute the study in Tuscany, a Region sufficiently advanced in the area.

A casual sample of 56 general practitioners from Livorno was selected by stratifying, in a proportional way, and considering the geographic position of the said practitioners (i.e. city centre/suburbs). The average age of the interviewees was 55, the majority of whom were male (83.9% male and only 16.1% female) a differentiation which was in accordance with the GP catchment area. The sample declared an average of 28 years of professional practice. This data is important because most interviewed physicians started to practice in the early 1980s and thus acquired significant experience in "traditional" ways of prescription and maintaining patients' health records.

From this larger set of physicians, we extracted 45 general practitioners and chose our patient catchment from their patient files. We chose to interview patients in GP waiting rooms in order to reproduce the number and the frequency of consultations. The interviews were conducted during week days (from Monday to Friday) both in the morning and in the afternoon so as to capture

<sup>2</sup> See Decision no. 1786/2002/EC; Communication COM(2004) 301; Communication COM (2004) 356; Recommendation no. 2008/594/EC; Communication COM(2008) 689.

<sup>3</sup> See articles 4 (f) and 5 (d) Directive 2011/24/EU.

<sup>4</sup> See article 14 Directive 2011/24/EU.

<sup>5</sup> "The set of health and social health data and digital documents generated by present and past clinical events related to a patient".

<sup>6</sup> See: SISS: [www.siss.regione.lombardia.it](http://www.siss.regione.lombardia.it).

<sup>7</sup> See: SOLE, Sanità On Line: [www.progetto-sole.it](http://www.progetto-sole.it).

<sup>8</sup> See: [www.regione.toscana.it/cartasanitaria](http://www.regione.toscana.it/cartasanitaria).

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