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Implementing the lifelong personal health record in a regionalised health information system: The case of Lombardy, Italy

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ABSTRACT

Background: The use of personal health records (PHRs) can help people make better health decisions and improves the quality of care by allowing access to and use of the information needed to communicate effectively with others concerning their health care.
Objective: This work presents the lifelong PHR system of the Lombardy region as an example of the implementation of an e-health solution that is capable of providing personal clinical documents from a lifelong perspective, integrating different healthcare providers over a large territory.
Methods: The lifelong PHR is embedded in the regional healthcare information system of Lombardy, which is characterised by a large and heterogeneous territory, a large number of different healthcare providers and organisations, and a significant population.
Results: The lifelong PHR makes clinical documents available to healthcare professionals and citizens when needed, and it is automatically updated with all of the documents regarding a clinical event regardless of which healthcare provider is currently taking care of the patient. Present statistics show that the lifelong PHR has experienced a wide diffusion in a short period of time, and at the end of 2010, it was active for more than five million Lombardy citizens. Digital reports and e-prescription transactions have almost doubled since 2007 and have reached a coverage of almost 100%.
Conclusions: The qualified and exhaustive collection of patient clinical data and documents should impact daily medical practice, as well as the care pathways and services provided to patients, and should help in the renewal of health assistance and the simplification of patients' access to care.

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1. Introduction

Making digital personal health-related data and documents effectively accessible and shareable amongst the appropriate stakeholders at the right time is one of the ways in which e-Health can help improve the safety, quality, and efficiency of care [1]. There has been increasing attention paid to the potential of personal health records (PHRs) to improve maintenance and availability of patient data [2]. In 2007, a joint position statement by the AMIA and AHIMA emphasised the value of the personal health record (PHR) as a "tool for collecting, tracking, and sharing important, up-to-date information about individuals' health or the health of someone in their care" [2–5]. The joint position stated: "a PHR helps people make better health decisions and improves the

quality of care by allowing them to access and use information that is needed to communicate effectively with others regarding their healthcare" [3].

PHRs substantially differ from Electronic Health Records (EHRs) in that they are personal collections of health-related documents of an individual or family, independent of which healthcare provider created the documents. Conversely, EHRs are collections of health and care documents that have been created and stored by single care providers in a digital form. The required secure storage of EHR information is ensured by the care provider itself. EHRs are used by healthcare professionals as planning tools that support the care process, from order entry to results management [6–8].

Whereas EHRs are limited to the time frame in which an individual is a "patient" and requires care, PHRs are "lifelong" because the period considered for the collection of documents is the entire life of the individual.

Although PHRs are "personal" collections, models of PHR systems are heterogeneous and vary in the extent to which the content of the record, the data/documents uploaded, and the rights of access are controlled by the patient or by a healthcare

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provider. Simple examples include the health and lifestyle record generated directly by the patient/family [9,10] (and managed by web applications or personal computers) or the records generated and stored within the healthcare provider through health kiosks or digital copies that the patient can access with read-only rights.

Currently, PHR systems are being used in Europe and the USA. There are examples of systems developed (1) by healthcare institutions, (2) by companies that are acting in the health-ICT business area, (3) by Governments, as well as (4) by large companies such as Google and Microsoft. As an example of (1), HealthConnectOnline, managed by the Kaiser Permanente care organisation, records information about allergies and immunisations, as well as laboratory results and past visits and can be used for appointment booking, prescription reordering, and email communication with healthcare professionals (http://xnet.kp.org/newscenter/aboutkp/ healthconnect/index.html). As an example of (2), in Europe, the LifeSensor product was developed by a health-ICT company and is available in Germany, Switzerland, Austria, and Bulgaria. Although it is not directly linked to the patient records of healthcare providers, it allows patients to store and manage information about their current health status, medical history, results, images, and documents. Authorised healthcare team members or caregivers can view, add, or update information (http://www.icw-global.com/de/ intercomponentware-ag/lifesensor-gesundheitsakte.html). As an example of (3), in the UK, the National Health System proposed NHS HealthSpace, which closed on March 31st 2013. NHS HealthSpace was an online personal health organiser and booking service, which was offered after email registration to people who lived in England and were older than 16. HealthSpace provided access to the Summary Care Record (SCR) containing important information taken from the electronic medical records held by the NHS. Currently, it is thought that the decision to close HealthSpace will not affect the SCRs, which had been created for 24 million citizens up to mid-March 2013. The main reason for closing the system was infrequent use. The data have now been securely destroyed as required by the Data Protection Act (http://www.connectingfor health.nhs.uk/systemsandservices/healthspace). The UK Department of Health is developing new strategies for better and personalised care, relying on improved information provision to all of the stakeholders of the healthcare process (http://informationstrategy. dh.gov.uk/). As an example of (4), Microsoft HealthVault allows patients to collect and store health information at a family level, and they may then choose to share that information with healthcare providers. In addition, apps and devices that are able to integrate data into the personal health record of a HealthVault user are available.

As an unsuccessful example, Google Health was a PHR system proposed by Google in 2008 and terminated in January 2012. The service was provided free of charge for anyone with a Google account. Personal health records could be created either by manually uploading or by integration with digital services provided by healthcare organisations who partnered with the initiative. Google Health merged personal separate health records into the user's Google Health profile, including allergies, medications, laboratory results (http://www.nytimes.com/2011/06/25/technology/25health. html?_r=0). There are various opinions regarding the reasons why the service was stopped. One is the limited use of the tool and its inability to meet patient's expectations regarding the automatic data upload and the management of prescriptions (http://readwrite.com/ 2011/06/24/google_health_why_its_ending_what_it_means). Others underline the difficulty of healthcare professionals in relying on the information included in Google Health, as well as the low number of healthcare providers and insurance companies that partnered with the initiative (http://searchenginewatch.com/article/2099923/Goo gle-Health-Shutting-Down-Doesnt-Mean-Google-Has-Abandoned- Health).

In 2007, the Italian government made the decision to push towards the adoption of a Lifelong PHR ("Fascicolo Sanitario Elettronico", in Italian).

In the Italian government definition, the lifelong PHR consists of a collection of all of the electronic documents regarding the healthcare of a single citizen, aimed at making the full and updated clinical documentation regarding a patient available to any healthcare provider, including in the case of emergency, regardless of which healthcare organisation produced the documents. The citizen is the owner of all of the data and documents included in the lifelong PHR and has the right to decide which documents should be included and who can access them. Hence, the model proposed by the Italian law can be considered a type of "integrated PHR" [11]: the patient owns the healthcare data/ documents and decides who has the right to access their lifelong PHR, but the record is updated with the documents created by different providers, without the patient's mediations, during the document upload process.

This model differs from all of the examples of PHRs described above in several ways: (1) it is not provided by a single healthcare institution, but it integrates the documents from all of the regional healthcare providers; (2) it is updated directly with original documents, without the patient's mediations and upload responsibility; (3) it provides citizens access to all of the documents regarding their health, and it can be integrated with other systems providing booking services and information; and (4) it is run on a public basis.

In Italy, because the government is in charge of drafting laws, whereas healthcare delivery is the responsibility of the regions, the real implementation of the lifelong PHR is regional and follows a guideline document that was issued in February 2011 [12]. In particular, the Lombardy region is one of the most advanced regions in Italy regarding the development of the regional healthcare and social service information system [13,14], and in 2010, the Lombardy region started the development of a full lifelong PHR.

The lifelong PHR developed in the Lombardy region now serves 10 million citizens, and it makes clinical documents available to healthcare professionals when needed, thus representing a success story in the PHR adoption scenario.

The aim of this work is to present the lifelong PHR system of the Lombardy region as an example of the implementation of an e-health solution that is capable of providing personal clinical documents in a lifelong perspective, integrating different healthcare providers over a large territory.

2. The Italian healthcare system and the Lombardy healthcare information system

The healthcare system in Italy is based on the public universal insurance model; it is sustained by taxation and is run on a regional basis. Each Italian region refers directly to the Central Government and covers healthcare costs for each Italian citizen assisted by the region. Costs for drug therapies, surgery, laboratory examinations, and all healthcare services are fully paid by the National Government.

Lombardy is located in the north of Italy, with a large, heterogeneous territory (23,863 Km^2) from the Po river valley to the Alps with almost 10 million citizens.

In Lombardy, healthcare organisations consist of hospitals and laboratories, either public or private, General Practitioner (GP) offices, private practices, and all of the facilities providing healthcare services to citizens. The "Local Healthcare Units" (ASL – Azienda Sanitaria Locale, in Italian) are committed to the administrative management of all of the services for healthcare and assistance in a specific geographical area within the region.