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Proposal for a Patient Centered Health Information Framework for Clinical and Personal Data Movement

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Abstract. This paper focuses on defining a framework to allow individual patients to track their own health related data. We propose a Patient Centered Information Framework (PCIF) allowing patient to manage their own data by using discharge letters. Discharge letters summarize information from a hospital stay, such as medical history, diagnoses, treatments and follow up, needed for continuity of care. It enables patients to share data with different organizations ensuring personal data protection, even when moving from different places and countries. A record of clinical management may thus be guaranteed when moving among different health structures as well as simplifying obtaining medications. We propose an approach to allow citizens to manage their health related data in a cross borders fashion. We compare the regulation of discharge letters among a sample of countries. We propose a management protocol for using a commonly adopted patient discharge letter framework within a PCIF.

Keyword. Patient, personal health record, information systems, discharge letter, international patient summary

1. Introduction

The increasing movement of citizens among different countries is highlighting the necessity of simplifying the process of health related information sharing among different countries. Indeed, even if personal and security related information are regulated by agreement among countries and institutions, health related information is still centralized into health structures (Electronic Health Records, EHRs) and government administrations of different countries.

The problem of moving information from one EHR to another has been considered in the literature [1]. Data exchange 'protocols' are aimed to enable health data

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integration between structures, however, data exchange ‘agreements’ between health structures belonging to different countries is necessary. Moreover, this necessitates keeping data consistent and updated, which is not always feasible. An example of such an architecture is the regulation for a ‘European Health Data Space’ (EHDS) that aims to make it easier to access and exchange health data across borders (European Council, 2023) by a cross-border digital infrastructure with a new platform, ‘HealthData@EU’ (https://ehds2pilot.eu/). Patients will have their electronic health data available via access points established by Member States [2]. However, this solution is very complex and expensive to be implemented at large scale.

In contrast, we propose a Patient Centered Information Framework (PCIF) allowing patient to manage their own data by using discharge letters. Discharge letters summarize information from a hospital stay and/or visit, such as medical history (including allergies), investigations, diagnosis, treatment, medication and instructions for follow-up, that are crucial for continuity of care.

2. Methods

We start by comparing the regulation of discharge letters among some countries. We then propose an alternative management within a PCIF using the patient’s own health data repository (OHDR). This will be illustrated by means of examples for individuals moving between countries.

3. Results

3.1. International regulation of discharge letters

There have been attempts to enable citizens to manage their data in their own health data repository. Companies such as Microsoft and Google tried to implement and propose frameworks in such a direction [3]. E.g., Google Health was launched as a framework to create a repository of health records and data (personal health record services). Even though the project was discontinued, it testifies to the importance of accessing health repositories and historical health records for individual patients [4].

In the UK, the National Health Service recommends healthcare professionals to send discharge letter to their patients [5]. However, there are barriers to compliance with these recommendations, such as physicians’ concerns about the reliability of the data (for instance, patients might alter the data). Also, the patient-physician relationship could suffer by communication issues due to information quality and reliability aspects [6,7].

In Australia, a nationwide information system [8] aims to ensure that patients have access to their medical data, including discharge letters. However, only 19% of discharge letters were uploaded into this national registry [9].

In France, discharge letters are sent to family doctors who are in charge of the process of patient health management. Until beginning of 2000, patients were not able to access their clinical data from health structures, and only family doctors were [10].

In Italy, discharge letters are furnished to patients with recommendations that further follow up and clinical treatment are the responsibilities of the patient and family doctor. The information is maintained in the Italian (both private and public) health structure to justify administrative reimbursement processes[11].

In summary, the importance of discharge letters within a health repository of the patient is recognized, but efforts to realize this have not yet been sufficiently effective.

3.2. Proposed framework

The proposed framework is mainly based on the use of the last available discharge letter as an international passport to track citizens' information for the next healthy interaction. The main idea is shown in Figure 1 where contexts are distinguished by means of European countries.

Within their own country the patient (e.g., citizens) shown in the left grey box in Figure 1 (same country) interacts with healthcare professionals (e.g., surgeon, dermatologist), as well as with health structures (e.g., hospitals, specialized units, clinics), insurance (e.g., health insurance, company insurance) [12].

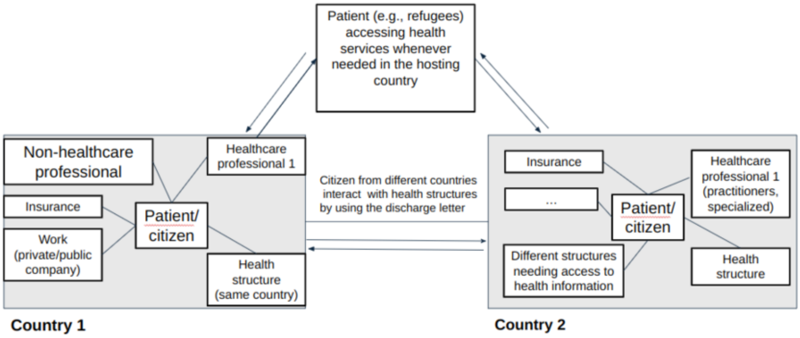

Figure 1. Illustration of the discharge letter framework: two case examples.
A refugee arriving in one country receives health support and then moves to another country. A citizen resident in one country, receives services on the country regulations and moves to different country with different health structure rules. The two grey boxes emphasize different structures and organizations.

Consider the following two use cases using examples of patients moving between countries. In the first example, a citizen is able to access their discharge letter from the country where they are resident, and would need care in the health service in the second country. By accessing their own discharge letter they may grant and give consent to the hosting structure access to the treatment protocol, thus access to this structured information and thus access to their health status and historical data. Any interventions by the hosting structure are detailed in the new and updated discharge letter, which they would be able to provide their own family doctor in their country, access to this updated information. This simple case is very relevant in the case of virus contamination where tracking the patient health status is vital [13].

In the second example we consider patients who have no citizen status, e.g., a refugee, arriving in a country where they receive their first screening, treatment and discharge letter with amnestic and historical information reported together with a management plan. In this case care and costs are dependent on this country's regulations. In Italy, a refugee receives an ad hoc (fiscal) code allowing the national health system to justify and keep track of costs, without needing further information from the patient. Refugees moving from one country to another one may use the discharge letter through the proposed framework to allow the hosting country to reconstruct their health history and management to enable them to receive a more precise and correct clinical management or drug protocol.

Figure 1 reports the scenario where health data may also be requested by other actors, such as insurance companies or employment registries, where health related information is needed for purposes other than direct patient care.

4. Discussion

A patient centered health information framework (PCIF) implies that individual patients have their own health data repository (OHDR) that contains the discharge letters from medical specialists. The discharge letter is used to provide citizens with information that they are in charge of, used both for managing their own health status as well as for providing information when requested (e.g., insurance companies, employment registry). Availability of discharge letters supports patients in managing their own healthcare [14].

Also, we consider patients who are not European citizens and need clinical and health related services such as a checkup status when arriving in a European country, as well as when moving between cities and countries. In this case the discharge letter containing information about the health status plays an important role for a citizen status requirement process. Similarly, a refugee arriving in one European country and moving to another, may use discharge letter information to provide useful data for a national citizen register. In this case, the first European country the refugee arrives in, is in charge of providing clinical care and health related screening, inserting data into a national health records database and to document health related costs and expenses.

From an informatics point of view, the discharge letter summarizes information about the hospital stay and visit, including investigation, medication, management and follow up, crucial for continuity of care. The structured discharge letter can thus be used as the most recent and thus updated health information summary, also useful to gather historic patient health information (i.e., timeline and health trajectories).

Discharge letters can be considered a uniformly structured piece of information suitable for comparison and aggregation over time. They contain significant information useful to the International Patient Summary (IPS) implementation [1] as a cross border information exchange mechanism [15].

Another advantage of the proposed framework is that it avoids the necessity for a complex, expensive, additional informational and governance system to ensure informed consent and privacy protection [16].

The information that has been obtained during the medical episode and the discharge letters should meet characteristics of a high quality record such as being complete, accurate, relevant, accessible, and timely (CARAT) [17]. The quality of discharge letters has been reviewed in different papers [7]. The letters are often measured in terms of country regulations and in terms of patient or family doctor comprehension. Different countries in Europe have their own regulations. Therefore, we propose an international policy for a uniform and consistent quality management of discharge letters.

The proposed framework ensures avoidance of identity security violation and supports citizens to keep track of their related data and simplify data retrieval regarding their health status, guaranteeing accessibility and reliability of discharge letters. Thus, the proposed framework guarantees safe and reliable data exchange with transparent access to implemented health protocols.

5. Conclusions

The aim of the proposed framework is to support citizens to keep track of data and simplify data retrieval regarding their health status. Accessibility and reliability are assured by security protocols to allow both citizen and hosting country in cross border movements to be confident about information sources produced by citizens and health structures. Finally, there are still many questions and the application of the proposed framework should be further investigated, considering the potential benefit for people and for health systems.

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