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What is This?
Electronic discharge summaries in cross-border care in the European Union: How close are we to making it happen?

N Döring1,2, P Doupi3, K Glonti4, J Winkelmann5, E Warren4, M McKee4 and C Knai4

Abstract

Introduction: The political drive for cross-border care within the European Union and an increasing focus on integrated care both have implications for electronic health records. The hospital discharge summary is a critical component of systems to ensure quality and continuity of care, and in a cross-border setting would particularly benefit from an electronic version. We have explored the extent to which European Union level policy and practice on electronic health records address issues pertinent to the development and implementation of electronic discharge summaries for patients treated outside their own country.

Methods: We approached the topic by analysing data from two different sources: European Union policy documents on topics relevant to electronic health records and deliverables of European Union-funded electronic health record-focused research and development projects. Elements pertinent to different aspects of interoperability – legal, semantic and technical – were extracted from both sources and their content compared to assess the degree of consistency between policy and implementation targets.

Results: We identified 25 policy documents and 14 European Union-funded projects. Our results show that European legislation is increasingly aligned with projects funded through European Union sources and substantial progress has been accomplished in achieving electronic communication across European health systems. Nevertheless, the achievement of a European level interoperable discharge summary is still a distant goal, while inadequate attention has been paid to the coordination of current discharge summary practices in Member States.

Discussion: If the harmonized European Union patient summary is also to function as an electronic discharge summary, further specific steps are needed that address issues of both content and processes related to communication.

Keywords

Electronic health records, discharge summary, European Union

Introduction

Borders in healthcare, whether organizational or geographical, are becoming less clearly defined. Since the 1970s, stimulated initially by several European court cases applying the principles of free movement of goods and services to healthcare,1 patient mobility was placed firmly on the European political agenda, with the legislative basis now set out in the Patient Rights Directive (2011/24/EU).2 While the scale of patient mobility across borders within the European Union (EU) is still very small,3 the growing mobility of citizens in general will have increasing implications for healthcare provision across borders.

There are several reasons why people obtain healthcare outside their country of residence: long waiting times, access to highly specialized treatment, lower
treatment costs and unplanned healthcare while being abroad, for example when on vacation. However, mobile patients will usually interact with providers in each Member State, for example with a primary care provider in their home country and a specialist provider in another one. Continuity of care requires that there is effective communication between care providers in each Member State involved. However, this demands interoperable systems that can deliver fast and secure data exchange.

An essential element in ensuring continuity and quality of care across borders is the care coordination defined as activities or approaches that bridge gaps along the care pathway aiming ‘to meet patients’ needs and preferences in the delivery of high-quality, high-value health care’. The transfer of information about the patient and his/her treatment among all those involved in the care process is indispensable to ensure optimal outcomes for the patient. Traditionally, the key means of transferring information between healthcare providers and patients has been the discharge summary, ideally providing a succinct résumé of a specific episode of care. Often, however, the information transmitted has been delayed, insufficient or inaccurate.

Where care takes place across national borders, such as those within the EU, the discharge summary has a particularly important role, as it details the hospital care received abroad, enabling the family doctor or specialist at home to build on care already received and plan further actions. Yet, what should be a simple process of transferring information from the hospital to the next care provider can be one of the weakest points in the cross-border care process.

One strategy currently being considered to improve care coordination and, in particular, the experience of being discharged, is the adoption of electronic discharge summaries. Directive 2011/24/EU ‘on the application of patients’ rights in cross-border care’ also specifies that a written or electronic record of the treatment received should be made accessible to every patient treated in another country. But until very recently there was no formal guidance as to what this record should contain. In November 2013, the eHealth Network achieved a major milestone, by adopting the first release of the ‘Minimum/non-exhaustive patient summary dataset for electronic exchange in accordance with the cross-border directive 2011/24/EU’. Yet while this is very important, as we shall show in this article, this is not yet adequate to ensure seamless cross-border discharge processes. In addition, the consistency in the format and content of discharge summaries used in each country has not been previously assessed.

The aim of this article is to explore the extent to which EU level policy and practice relevant to electronic health records (EHRs) addresses issues pertinent to the development and implementation of electronic discharge summaries in the context of cross-border care. By charting which aspects have been or are already being addressed by EU projects and juxtaposing them with findings of prior studies regarding the content and implementation requirements of discharge summaries, we have identified issues that remain unresolved or are only partially addressed, and translated these gaps into proposals for future research and policy priorities and actions.

**Methods**

We approached the topic by analysing data from two different sources: first, EU policy documents on topics relevant to EHRs, and second, EU-funded EHR-focused research and development projects, where we sought to establish the extent to which policy priorities are reflected in practical actions.

In order to identify all relevant policy documents in the EU arena, two independent reviewers (ND and JW) searched relevant EU web pages and ran a search via the Google search engine. Combinations of the following keywords were used: electronic health records, telemedicine, medical records, ICT (Information and communications technology) and healthcare. Policy documents were included when they focused on EHRs, addressed the EU’s aims for EHRs (continuity of care, reduced healthcare costs, closer collaboration, quality of care) or explored factors hindering or facilitating the widespread use of EHR in Europe. We took as given the articles in the treaties establishing the legal basis for action (i.e. 168 TFEU, 28–30 TFEU) and excluded press releases and obsolete policy documents that have since been revised. We restricted the search to documents published within the period 2002–2012. The reviewers applied the inclusion and exclusion criteria to the titles and, where available, summaries identified in the search.

After title and abstract screening was complete, the reviewers assessed the full set of potentially eligible documents. One reviewer (ND) read through all the documents included and created a data extraction template to capture relevant information. The template was pre-tested with a small sample of documents and revised. The final extraction table contained the following sections: (1) name of document, (2) year, (3) overall aim, (4) EHR relevance, (5) relevant definition provided, (6) direction for future EU policies, (7) aspects concerning legal interoperability, (8) aspects concerning semantic interoperability, (9) aspects concerning technical interoperability, (10) finances and (11) cross-border aspects.

Two teams of reviewers (ND and JW/CK and EW) then extracted data independently. Disagreements were resolved by discussion and consensus. The information
entered in the extraction table was then annotated and summarized by the other team (ND and JW/CW and EW), respectively, providing a second assessment of the content. Interoperability of EHR systems, defined as ‘the ability of two or more eHealth systems to use and exchange both computer interpretable data and human understandable data and knowledge’,21 is the central prerequisite for the development and implementation of electronic discharge summaries in the cross-border setting. Hence, we organized the main findings of our analysis according to the three key areas of interoperability: legal/regulatory, semantic and technical.

In addition, we reviewed the key EU funded projects on EHRs. In order to produce a comprehensive and complete list of relevant EHR-related EU-funded projects, an extensive search of information on the web was performed. The EU online database ‘Cordis’ (Community Research and Development Information Service) is the official source of information about most research projects and therefore was a primary source of information (http://cordis.europa.eu/projects/home_en.html). Key results of projects were assembled and briefly summarized, including aims, objectives and links to EU policy. Subsequently, one researcher (PD) reviewed the outputs of key projects to identify findings with relevance to the development and implementation of an electronic discharge summary in the cross-border setting, focusing on the aforementioned key interoperability areas.

Results

In total, 25 documents (Table 1) were identified as directly or indirectly informative about the European

<table>
<thead>
<tr>
<th>Registration and reference</th>
<th>Name (short version)</th>
<th>Type</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>HLCH/2003/1/724</td>
<td>Final report</td>
<td>High Level Committee on Health Report</td>
<td>2003</td>
</tr>
<tr>
<td>00323/07/EN WP 13127</td>
<td>The processing of personal data relating to health in electronic health records (EHR)</td>
<td>Working Document</td>
<td>2007</td>
</tr>
<tr>
<td>COM (2008) 689 final28</td>
<td>Telemedicine for the benefit of patients, healthcare systems and society</td>
<td>Commission Communication</td>
<td>2008</td>
</tr>
<tr>
<td>2008/49/EC30</td>
<td>The implementation of the Internal Market Information (IMI) System as regards the protection of personal data</td>
<td>Commission Decision</td>
<td>2008</td>
</tr>
<tr>
<td>2009/C 302/06333</td>
<td>Safe and efficient healthcare through eHealth</td>
<td>Council Conclusion</td>
<td>2009</td>
</tr>
<tr>
<td>Council of the European Union34</td>
<td>Post-i2010 Strategy – towards an open, green and competitive knowledge society</td>
<td>Council Conclusion</td>
<td>2009</td>
</tr>
</tbody>
</table>

(continued)
We found few policy documents that specifically address EHRs (e.g., European Commission recommendations on cross-border interoperability of EHRs, a Working Document on the processing of personal data relating to the EHR), but EHR developments are addressed in or affected by activities in other policy domains, such as services, general technology/ICT or privacy. The strong political priority to advance eHealth solutions, as seen in the analysis of policy documents, is also reflected in the range of projects funded by the European Commission. We reviewed a total of 14 EU-funded projects dealing with EHRs (Table 2) and present next their main points of relevance for a cross-border electronic discharge summary grouped in four ‘clusters’, together with the pertinent findings of the policy documentation analysis.

### EHR policy and implementation landscape

The 2004 eHealth Action Plan for the EU is the first formal commitment by Member States to cooperate more closely in the area of eHealth. The Action Plan called for establishing structures and conditions to enable the flow of information between interoperable systems across Europe, with a key goal of fostering the development and implementation of national eHealth policies and strategies, thus stimulating research and implementation efforts at national and EU levels.

These original objectives have been reinforced by the 2020 eHealth Action Plan, which sets out to strengthen existing commitments and respond to changing market and behavioural trends, with individuals now able to monitor their health and well-being online or through...

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#### Table 1. Continued.

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<thead>
<tr>
<th>Registration and reference</th>
<th>Name (short version)</th>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>COM (2010) 170 final³⁸</td>
<td>The state of data protection in the Internal Market Information System</td>
<td>Commission Report</td>
</tr>
<tr>
<td>2011/24/EU²</td>
<td>Patients’ rights in cross-border healthcare</td>
<td>Directive</td>
</tr>
<tr>
<td>2011/0299 (COD)¹⁰</td>
<td>Guidelines for trans-European telecommunications networks</td>
<td>Proposal For Regulation</td>
</tr>
<tr>
<td>2011/890/EU¹¹</td>
<td>Network of national responsible authorities on eHealth</td>
<td>Commission Decision</td>
</tr>
<tr>
<td>COM (2012) 238 final⁴²</td>
<td>Electronic identification and trust services for electronic transactions in the Internal Market</td>
<td>Proposal For Regulation</td>
</tr>
<tr>
<td>2012/C 198/06⁴³</td>
<td>Multi-sectorial and independent expert panel to provide advice on effective ways of investing in health</td>
<td>Commission Decision</td>
</tr>
<tr>
<td>European Commission – IP/12/453 07/05/2012⁴⁴</td>
<td>eHealth Task Force report – eHealth 2020</td>
<td>eHealth Task Force</td>
</tr>
</tbody>
</table>

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Döring et al.
### Table 2. Overview of EU-funded projects related to EHR.

<table>
<thead>
<tr>
<th>Project name</th>
<th>Funding and Reference</th>
<th>Findings of relevance for discharge summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Descriptive, monitoring projects - best practice identification</td>
<td></td>
<td>EHR a policy priority in the majority of countries, implementation more limited</td>
</tr>
<tr>
<td>eHealth ERA</td>
<td></td>
<td>Found that patient summary was in routine use in seven EU countries and in implementation phase in five (out of 34 studied). A survey highlighted variations in the summaries’ components and roles</td>
</tr>
<tr>
<td>eHealth Strategies + eHealth ERA, 2009 (EC, DG INFSO, ICT for Health Unit)</td>
<td></td>
<td>Identified one example of implementation that is of relevance for the discharge process: the operations of the MedCom network in Denmark, a patient summary but relevant for the discharge summary content</td>
</tr>
<tr>
<td>eHealth – IMPACT, 2005 DG INFSO 2004/S159-137695</td>
<td></td>
<td>Viewed EHR as the main instrument to enable improved coordination and continuity of healthcare between ambulatory care and hospitals</td>
</tr>
<tr>
<td>EHR – Implement, 2010 PHEA/CEC, 2006112</td>
<td></td>
<td>Identified one example of implementation that is of relevance for the discharge process: and the Emergency Care Summary of NHS Scotland, a patient summary but relevant for the discharge summary content</td>
</tr>
<tr>
<td>EHR-Impact, 2008 DG INFSO and Media, unit ICT for Health</td>
<td></td>
<td>European hospitals lagging behind US counterparts in the area of discharge summaries; integrated system to send electronic discharge letters = 42% of hospitals, ePrescribing (also for discharge medications) = 30% (potential gap where the systems are in place but are not yet as much in use) – university hospitals much better than average Investment priority in coming 3 years = 48%</td>
</tr>
<tr>
<td>eHealth Benchmarking study III, 2011 DG Information Society and Media</td>
<td></td>
<td>The patient summary was recognized as a priority for European countries but the agreed patient data set only includes patient clinical data optionally</td>
</tr>
<tr>
<td>epSOS, 2013 Co-funded by EC (CIP) within the ICT Policy Support Program</td>
<td></td>
<td>Proposed a comprehensive model on European interoperability, EU eHealth Interoperability Roadmap, which underscores the importance of supportive infrastructural arrangements and clear incentive structures to support continuity of care along to spectrum of care</td>
</tr>
<tr>
<td>eHealth Interop, also called Mandate 403 –, 2009 CEN/ITC 25</td>
<td></td>
<td>Addresses issues around the requirements for achieving semantic interoperability in the context of patient summary</td>
</tr>
<tr>
<td>eHGI – eHealth Governance Initiative, 2011–2014 EC (Joint Action and Thematic Network)</td>
<td></td>
<td>Builds on the work of the Calliope project</td>
</tr>
<tr>
<td>eHealth Innovation-Thematic Network, 2013 EC’s ICT-PSP-program</td>
<td></td>
<td>Set of functional statements translated in 16 languages</td>
</tr>
<tr>
<td>Projects on technical interoperability</td>
<td></td>
<td>Fragmentation and lack of maturity in interoperability test tools and test plans concerning: terminologies, exchange and sharing of EHRs, identification, authentication, signatures and structured documents</td>
</tr>
</tbody>
</table>

(continued)
devices such as smartphones. The Action Plan also calls on Member States to implement organizational changes that will make patient-centric eHealth solutions an integral part of their healthcare systems.62

This steady rise in the national policy focus on EHR systems was illustrated by the findings of the eHealth ERA45 and eHealth Strategies46 projects, which also demonstrated how the step from policy prioritization to field implementation is a long and difficult one. The eHealth ERA project63 found that most EU Member States had published official policy documents on their eHealth implementation strategy. In terms of EHR implementation across Europe, there was a range of EHR systems in place or under development in most European countries.64–66 These systems were mainly being used by individual healthcare providers and not being rolled out at national level.67 Lessons from the very few established national EHR programmes suggested that the experience of using the data from EHRs fed back to improve the quality of the record.66 Findings from a survey among Member States highlighted variations in patient summaries’ components and roles, e.g. to support unexpected contacts, or to support continuity of care along shared clinical pathways, as well as planned chronic care and clinical governance.45 The results were used to produce a first iteration of a patient summary template. The follow-up project to eHealth ERA–eHealth Strategies46,61 set out to analyse policy development, planning and implementation measures with respect to eHealth systems in EU countries. It found examples in some countries of concrete steps towards implementing eHealth solutions since the end of the eHealth ERA project.46 The EHR had maintained its status as a prominent policy priority, now though combined with increased emphasis on assessment and evaluation. At the time (2009) the patient summary was in routine use, to some extent, in seven EU countries and in an implementation phase in five (out of 34 studied). A growing interest in matters of patient and professional identification, standards and interoperability was noted. The challenges of implementation were confirmed by the findings of the Benchmarking study: level of IT (Information technology) uptake in EU hospitals.33 Although there had been some progress compared to studies undertaken 5 years earlier, European hospitals were found to be lagging behind their American counterparts in the area of discharge summaries. Integrated systems for sending electronic discharge letters were available in an estimated 42% hospitals of the then 30 European Economic Area countries (according to their CIOs (Chief information officer)), but used for communication with general practitioners by only 32% of them (according to medical directors). The finding indicated a large gap between the availability and take-up of systems in the hospitals surveyed. Electronic discharge summary systems were identified as a priority for investment in the subsequent 3-year period in 48% of hospitals. Ireland’s national general practitioner messaging project was recognized as an example of best practice among Member States, with its electronic communication system linking primary and secondary care. The eHealth Impact47 and EHR Impact49 projects focused on developing methodologies for measuring the (socio)-economic impact of eHealth/EHR applications and testing them in specific case studies. Each identified one example of implementation relevant to the discharge process: the operations of the MedCom network in Denmark and the Emergency Care Summary of NHS Scotland (National Health Service), respectively. In the MedCom solution, data are transferred from general practices to other service points where citizens may need access to their information, such as discharge from hospital and transfer to home care and residential care services. The transfer of data relies on interface specification agreements and certification of software compliance with agreed standards and syntax, which in turn ensure the efficiency of data exchange between healthcare, social care and other service providers. The NHS Scotland Emergency Care Summary is essentially a patient summary record for the five million population of Scotland. The basic data included at

Table 2. Continued.

<table>
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<tr>
<th>Project name</th>
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</table>

Do¨ring et al.
the time of the study were demographics, personal information, medications, allergies and adverse reactions, while extensions planned (for 2008) were diagnostic test results, vital signs, dentists’ prescriptions, nursing care plans, palliative care data, hospital prescriptions and use of over-the-counter drugs. The eHealth Implement study further confirmed that the EHR has been viewed as the main instrument to enable improved coordination and continuity of healthcare between ambulatory care and hospitals. However, even though data exchanges between institutions do appear in the national level ICT strategies or policies, they are rarely implemented at the institutional level.

The large-scale pilot project epSOS (Smart Open Services for European Patients) has concentrated on developing a trusted domain for eHealth where health data exchanges are channelled through national nodes. It provides recommendations, technical specifications, system descriptions, organization models, software and software tools to improve the interoperability and cross-border access to ‘Patient Summaries’, a minimum set of a patient’s data which would provide a health professional with the essential information needed in case of unexpected or unscheduled care, and also planned care. The patient summary was recognized as a priority for European countries as a way to establish eHealth interoperability. epSOS undertook Member State level surveys on two separate occasions (spring 2009 and February 2012). The results of the surveys revealed many ongoing activities, but at the same time a scarcity of actual functional implementations of ePrescriptions and patient summaries. Significant differences in structuring and coding the necessary information elements were identified, combined with a dominance of free text documentation and major difficulties in retrieving the required information on patient encounters. It was thus concluded that the goals set for the project would not be achieved by 2013.

**Legal interoperability**

Individual health data must be protected from misuse and/or unauthorized access. The same laws protecting paper-based individual health information apply to EHR data in Europe. The EU Directive on Data Protection (95/46/EC) was the starting point to harmonize national provisions on protection of individuals in processing and free movement of personal data. The Directive was adopted to ensure the free flow of data while ensuring the individual’s fundamental right to protection of their data. Article 8 of the Directive states that the processing of personal health data is prohibited unless it is for the provision of healthcare and processed by healthcare professionals. The directive has been implemented in all EU countries and is currently in the process of revision. In January 2012 the European Commission made its proposal for a new Data Protection legislative framework, including two statutes: General Data Protection Regulation and Data Protection Directive. Several of the proposed amendments concern articles related to the use of health data (Article 81) as well as statistical and scientific research purposes (Article 83). After a lengthy period of negotiation among the committees concerned with the issues involved, the European Parliament approved a modified text of the proposed Regulation, the final text of which is now awaiting agreement from the Council of Ministers. Data protection is also anchored in the Lisbon Treaty Article 16 (TFEU) whereby ‘everybody has the right to protection of personal data concerning them’. Additionally, the legally binding Charter of Fundamental Rights of the EU stresses, in Article 8, individual rights to data protection. Technological advances require new approaches to overcome the new threats to data protection and security, as has been graphically illustrated by revelations of widespread abuses by some national security services.

While Member States shall not restrict the flow of data, it is necessary to take into account the different rights of privacy and personal data protection of citizens or residents of different EU countries, which may hinder the transmission of data across borders. The Council conclusion of 2009 encourages Member States to create legal clarity and to ensure compatibility of health data protection, including legal constraints for safe exchange of healthcare data across borders. The Council conclusion of 2010 recognized that data privacy and protection need to be respected by emerging service innovations. The Commission Communication of 2010 on personal data protection aims to develop a consistent and comprehensive approach to individual rights to data protection within the EU. It addresses also the need to revise existing laws of sensitive data, including health data in regard to technological developments. The Commission therefore visualizes further clarification and harmonization of the conditions allowing the processing of sensitive data. Furthermore, the Commission states that data transparency is one of the key means by which individuals can exercise control over their personal data. It is important for data transparency that data controllers inform individuals about who collects and processes their data.

**Semantic interoperability**

The Commission recommendation on cross-border interoperability of EHR systems (2008) is intended to provide Member States with the basic principles to address semantic interoperability. According to the Commission, agreements on standards for
semantic interoperability, with data structures and subsets of terminology systems are needed to make exchange of health information meaningful. The Council Conclusion (2009) emphasizes the need to adopt common medical terms for the exchange of medical data between Member States.

The task of the Semantic Health Project was to develop a longer term research and deployment roadmap for semantic interoperability. The project focused on what it described as ‘the core applications of patient summary and electronic prescribing as “gate-openers” to progress on interoperability across Member States’.58 The project recommended that the highest level of interoperability (Level 3 – full semantic interoperability, sharable context, seamless co-operability) should be sought in specific areas of clinical practice that are known to be of high patient safety risk, and in priority areas such as care transfers and referrals and care coordination. The Thematic Network project, Semantic Health Net is ongoing and considers the discharge process as an essential component of treatment guidelines.59,74 They note that lack of communication between hospital and community or outpatient specialists can lead to inappropriate care and inadequate follow-up. They recommend that providers should be notified when patients with heart failure (one of the clinical scenarios addressed by the project) are admitted and discharged to hospital, regardless of the reason for admission, and that hospital data should also be accessible from the general practitioner and outpatient services. In Semantic HealthNet’s Use Case 1 (Data transfer), different options for achieving semantic interoperability (through use of different standards) are explored, but still on a theoretical level.75

The eHealth Mandate M/403 project, bringing together all major European standardization organizations (CEN (European Committee for Standardization), CENELEC (European Committee for Electrotechnical Standardization) and ETSI (European Telecommunications Standards Institute), in its eHealth-INTEROP Report76 addressed several issues related to requirements for achieving semantic interoperability in general and, more specifically, in the context of patient summary and emergency data sets, and underlined the significant challenges to be overcome in order to achieve true semantic interoperability in a multicultural and multilingual environment, such as provision of cross-border healthcare services. The Calliope network (Call for InterOPERability) proposed a comprehensive model of European interoperability, the ‘EU eHealth Interoperability Roadmap’ to accelerate eHealth deployment across and between countries.51,52 The project Roadmap underscores the importance of supportive infrastructural arrangements and clear incentive structures to support continuity of care along the whole spectrum of care. Building on the work of Calliope, the eHealth Governance Initiative aims to speed up the adoption process of eID (electronic identity card) EU governance mechanisms; streamline policy and uptake; and enable the development, integration and European-wide deployment of interoperable eHealth services and infrastructures.54

Technical interoperability

The final report of the Health Telematics Working Group of the high Level Committee of health from 2003 had already identified the need for functional interoperability (or at least documented standardized interfaces).24 The Working Group suggested that this can only be achieved at a European level. Furthermore, it suggested a forum in which Member States could meet and exchange experiences. The need for cross-border interoperability in other technical areas, such as electronic identities and signatures, was also identified. Nevertheless, communication between different healthcare providers is still often done manually, with non-interoperability taking more time but also increasing the risk of medical errors. The Internal Market Information (IMI) System, as a secure internet application, aims to improve the efficiency of administrative cooperation and communication in Europe. The first pilot started in 2007. A 2008 Commission decision defines the rights and obligations of IMI users. It is to be seen how far it can facilitate the interoperability of EHR. The Recommendation on Interoperability of Electronic Health Record Systems (COM (2008) 3282) calls not only for interoperability at regional and national level, but also at EU level.77

In order to support deployment of EHR systems certification, the EHR-QTN (Thematic network on quality labelling and certification of EHR systems) thematic network produced a repository of over 1,700 functional ‘descriptive statements’, a subset of which has been translated in 19 languages (EHR-QTN, 2012).56 The repository contains both generic provisions and statements on ‘specialised’ areas such as ‘requirements for EHR systems as source for clinical trials data’ or ‘medication-related decision support’. The functional statements of EHR-QTN are not in the public domain; hence it was not possible to assess the extent to which they address discharge summary-specific needs. The project also placed emphasis on the need for cross-border recognition of quality labelling and certification, for which it produced a validation service (EuroRec Seal, http://www.eurorec.org/services/seal/). The HITCH project (Healthcare Interoperability Testing and Conformance Harmonisation) reviewed over 30 Open Source tools and libraries of interest, in the context of interoperability conformance testing of healthcare
information systems. Of the project findings, the fragmented and underdeveloped state of test tools and test plans in areas such as terminology services, exchange and sharing of electronic records, identification, authentication and signature, structured documents (laboratory, oncology and other specialties) is particularly relevant to discharge summaries. The project recommended increased collaboration between functional and interoperability focused initiatives in order to avoid overlaps.

Discussion

The EU has shown remarkable perseverance in the pursuit of eHealth applications and, specifically, EHRs. As we show, a variety of policy instruments have been used in concert: information and guidance (communications, working papers and reports), legislation (directives and regulations) and financial support (of research and development projects), with funded projects increasingly aligned with European legislation. Projects are becoming larger, with wider participation of Member States.

Earlier studies have examined issues related to discharge summaries in a cross-border context, but our study is the first specifically exploring progress towards a cross-border electronic discharge summary in the EU. The European MARQuIS project on Methods of Assessing Response to Quality Improvement Strategies studied care abroad from patient and healthcare provider perspectives. It underlined the need for common standards on the type and timeliness of information provided at discharge by hospitals in Europe, both to patients and to the healthcare providers receiving them, advocating a standardized European discharge summary, with the hospital discharge summary for patients crossing borders in the patient’s language, or at least in English. The HANDOVER project (http://www.handover.eu/upload/library/n3p29v3hn3sultn0htqd.pdf) focused specifically on the interface between hospital and community (general practice) care, and hence included both aspects of referral to specialized care and of the subsequent discharge from hospital inpatient care to the community. Although the project explicitly excluded situations relating to ‘cross-border handover’ of patients, it nevertheless analysed the handover landscape across several EU Member States, thus providing useful background information. Specifically, the project showed that, in spite of national differences in phasing, role of patients and tools used, there is agreement among stakeholders on the content of discharge documentation. In addition, the project clearly outlined the double role of IT systems in the discharge process, both as a facilitator of up-to-date and timely transfer of information and as an impediment to information flow, due to interoperability problems and infrastructure constraints.

Our research builds on themes identified by earlier work to further focus on specific issues associated with electronic discharge summaries, by studying the alignment of EU legislation with EU-funded projects on electronic patient data exchange, of which discharge summaries form a subset. It has some limitations. Our analysis relied on EU policy documents and data on EU-funded projects that could be retrieved through online sources. The CORDIS database is the official depository for EU-funded research but is known to have many weaknesses. However, there is no alternative source. Although highly unlikely, we cannot exclude the possibility that there have been other political developments that resulted in EU legislation and have not been distributed online. Furthermore, we have chosen to only include EU-funded projects. We do not have information on projects funded from other sources. We had chosen 2002 as the starting date for the review to capture policy developments most relevant to the 2004 eHealth Action plan, although some political developments would have taken place (long) before the eHealth agenda influenced the later developments in the field of electronic discharge summaries. The extraction of data was done by independent researchers to enhance reliability.

The ambition to achieve electronic communication across European health systems is clear in the documents reviewed and evidenced by the progress accomplished. However, there is much more to be done given the directive on the application of patients’ rights in cross-border healthcare and its requirement for a harmonized patient summary within the EU. The need for further action is particularly urgent if the patient summary is also to assume the functions of the discharge summary. Factors hindering the implementation of the EHR also impede the implementation of EU-wide electronic discharge summaries. This was highlighted by an exploratory study on discharge summary use across Europe, which also highlighted the challenges in developing a European harmonized discharge summary. It found that research on discharge summary content and use remains confined within organizational or national boundaries and that national discharge summary standards vary widely. There was, however, agreement on core categories of information that should be included, identifying minimal data requirements that could be agreed upon for use in a harmonized European discharge record. However, there is a need for internationally recognized classifications; for example there is currently no internationally agreed system of procedure coding.

Thus, despite concerted efforts to develop structures and systems supportive of interoperable electronic
medical record systems across Europe and the alignment of policy developments and project funding, there is still limited attention to content and related workflow processes and practices. While epSOS is currently making considerable efforts to create a harmonized minimum data set for patient summaries within the EU, this will be insufficient to achieve continuity of care and true patient engagement. That would require certain issues related to (electronic) discharge summaries to be addressed. The priority given to how this is to be done should match that given to agreeing on the content of what is being communicated. The Patient Summary of epSOS – when used in the context of planned care – could be seen as fulfilling the role of the referral letter. Although the project includes clinical data in the summary, at present this is only optional. The Health Care Encounter Report (HCER), added later to the palette of epSOS document types, is closer to the cross-border discharge summary concept, since it is generated in the country of treatment, and returned to the patient’s country of affiliation. The HCER is still in the early stages of development. Nevertheless, results already obtained provide additional support to the conclusion of our research, noting that ‘national workflows and administrative procedures must be in place in order to receive the information [of the HCER] and integrate it into the local system and furthermore into the Patient Summary of a patient’, as well as the need to clarify ‘what kind of data should be sent back to country A in a HCER’ – in other words, the definition of the HCER content (http://www.eposos.eu/uploads/tx_epsosfileshare/D1.2.2_epSOStools_baselineevaluationresults_epSO-SII.pdf).

This study has shown that EU actions are increasingly aligned and have contributed to the development and implementation of eHealth applications and, thus, to the development of electronic discharge summaries. However, the establishment of EU-wide electronic discharge summaries is still at a very early stage. Some prerequisites are in place but others need much more work before the next steps can be taken. There are hopes that the Trillium Bridge project, funded as part of the Transatlantic eHealth/health IT Cooperation Memorandum of Understanding and Roadmap and the Digital Agenda for Europe (www.trilliumbridge.eu, running until February 2015) may contribute to taking this forward. Trillium Bridge is exploring interoperability between European Patient Summaries in the EU and Meaningful Use II Transitions of Care in the United States, in order to enable the sharing of basic patient data between health professionals on both sides of the Atlantic. Given that the US Summary of Care record is essentially a discharge summary, it is to be expected that EU initiatives will also need to look more carefully into electronic discharge documentation. Research is needed to map the legal and regulatory situation regarding hospital-to-community discharge within Member States. In parallel, an in-depth assessment of existing guidelines on discharge summary content should be conducted. Further research is also required to ascertain best practice in communication at discharge, for example via a discharge nurse, shared care across the primary–secondary care interface and to understand whether there are lessons to be learned from various discharge summaries, e.g. nursing discharge summaries versus medical discharge summaries, in identifying the core data set for a harmonized European electronic discharge summary.

Conflict of interest

None declared.

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Notes

a. Data on cross-border healthcare is incomplete and highly fragmented but DG Sanco has estimated that the demand for cross-border healthcare still only accounts for about 1% of public spending on healthcare (see http://europa.eu/rapid/press-release_MEMO-13-918_en.htm).
b. ‘Development and implementation’ refers to electronic discharge summaries; the word ‘development’ is pertinent because they are not broadly in use yet and the relevant software needs to be produced (or ‘developed’). The phrase ‘content and implementation requirements’ refers instead to the paper discharge summaries current in use.
c. This refers to all possible applications of information technology to healthcare services and systems.
d. Overall since 1988, the European Commission has supported over 450 projects on medical informatics, health telematics and eHealth worth more than €1 billion.

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