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A Survey on Shared Electronic Health Record Architectures in Europe

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Abstract

The EU e-Health action plan has initiated activities across Europe for e-Health and the creation of Shared Electronic Health Records (SEHR). Most of the member states are preparing or already have roadmaps and programs. Information on these activities, especially on the more technical aspects, is of great importance for informed decision making but very hard to find – due to the early stages and transitory phases in which those programs are currently in, with communication being considered no priority. To gain first hand insight, a survey was conducted amongst active experts in the field of SEHR, identified by having given topical presentations at selected international conferences in 2006. The survey was conducted online, with 35 participants (19.4 % of all approached) answering the questionnaire on general e-Health strategy, the SEHR program in general and technical aspects of the program. Of the participants, 80% know of an SEHR program in their country they could answer questions on. The majority judges the programs to be in their early stages and is sceptical against official statements for program completion timeframes. Trans-national (EU level) interoperability is only seen by 56% of the participants as an issue. The Internet protocol is exclusively seen as means of transport for the exchange of SEHR data. The majority foresees a mostly decentral federated architecture with central patient index, but federated metadata registries and data repositories for the SEHR. HL7 V3 CDA, DICOM and IHE XDS achieve highest ranking as standards and technical frameworks for realization of the SEHR. SEHR projects currently are in an early stage where specifications are not finalized and still subject to change. Research and pilot projects, that have in some cases been initiated more than a decade ago, are present in some countries giving directions for how pervasive solutions could work and have to be incorporated into future infrastructures.

Keywords:

electronic health records, e-Health, IHE, system architecture

Introduction

In its 2004 e-Health action plan [1], aligned with the eEurope action plan [2], the commission of the EU set ambitious goal to establish a European e-Health infrastructure until 2009. Several measures were defined, amongst them the development of national or regional roadmaps for e-Health by each member state by the end of 2005, the definition of a common approach to patient identification and interoperability standards for health data messages and electronic health records by the end of 2006, the deployment of health information networks for e-Health in the period 2004-2008, the provision of online services such as teleconsultation, e-prescription, e-referral, telemonitoring and telecare by the majority of European health organisations by the end of 2008, and a baseline for a standardised European qualification for e-Health services in clinical and administrative settings by the end of 2009.

This has sparked substantial activities among the EU member states, with a large variety of national and regional projects being started (see for instance [3] for the work on e-Health strategy in Austria).

One of the key elements for e-Health strategies is to establish a Shared Electronic Health Record (SEHR) for all citizens, meaning that elevant health related data for citizens is electronically shared across different providers in all the sectors of healthcare. Substantial benefits in terms of quality and productivity in a collaborative care setting are enabled by such infrastructure [4] and seen as indispensable in the future health system [5]

Even though the commission has also agreed in the e-Health action plan, that it will publish a study on the state of the art in deployment, examples of best practices, and the associated benefits biannually in the period 2004-2010 for benchmarking already resulting in valuable studies eg. in the e-Health ERA project [6,7,8], it is still very hard to find information on the functional and technical approaches pursued in the member states in the establishment of shared electronic health records. Studies on certain aspects of shared electronic health records with special focus on EU-wide interoperability like the one on patient summaries conducted in the e-Health ERA project [9] have become available, but also here, only 9 official state-

ments (by the national Ministry of Health or the national e-Health competence centre) were received and issues of health record system architecture were not considered.

Methods

Since information on the various approaches to these technical aspects are of great interest for those contributing to SEHR projects themselves, and currently reports are rarely available, a survey with this focus was made amongst those experts working on SEHR projects to collect their opinion on the scope and status of these projects. It is also interesting to see how e-Health strategies an SEHR programs are viewed by national experts, sometimes in disagreement with the statements of national strategies.

For the recruitment of participants for that survey, persons were identified who had either authored or co-authored papers related SEHR given at various conferences[1] in 2006 (to ensure that they are currently actively involved in this field) or who are representatives of national competence centres for e-Health. Additionally, the national representatives of EFMI (European Federation of Medical Informatics) were approached. Since the survey was conducted online, 180 persons were invited via email to participate on Nov 2 2006. With a reminder after one week, the survey was answered by 35 participants (19.4%) unt it was closed on Nov 20 2006.

Scope of the survey and participation

The online survey was composed of 23 questions in there groups: general questions on the e-Health program, questions on the SEHR program, questions on the SEHR architecture and functionality.

The 35 participants were from 18 countries – mostly European, with additional participation from Russia and Israel (5 from AT and NO, 4 from DE, 3 from IT, 2 from CH, DK, EE, SE, and 1 from FI, FR, GR, IL, IS, LT, PL, PT, RO, RU).

The participant judged themselves mostly as competent or very competent to answer the survey (Table 1):

Table 1 – Competence of participants

How competent do you feel to make statements on the national eHealth strategy with regard to shared electronic health records in that country?	participants
very competent (ie. actively involved in the national e-Health effort)	16 (46%)
competent (ie. expert on the subject with good insight into the national e-Health effort)	9 (26%)
slightly competent (ie. involved in certain aspects of the national e-Health effort)	9 (26%)
not competent (ie. not involved with the national e-Health effort)	1 (2%)

Of those 28 participants who stated there is an SEHR program in their country, their involvement with this program was characterized as described in Table 2:

Table 2 – Involvement in SEHR program

How are you involved with this SEHR program?	participants
Decision maker	3 (11 %)
Consultant	10 (36%)
Program team member	4 (14%)
Member of a stakeholder organization of the program	3 (11%)
Other - not directly affiliated with the program	8 (28%)

Since there were several participants from some of the countries, the agreement between those participants from the same country on selected questions could be determined to have a measure for the reliability of the survey results. The agreement was determined as the percentage of participants from one country giving the top ranking answer for one of 7 selected questions[2]. Taking the arithmetic mean of these values, an overall agreement of 79% was found. This indicates that there is generally a good consensus accurately reflecting the e-Health situation, but it also shows that there is a certain controversy in the expert opinion caused mainly by the transitory phase in which most of the countries are with respect to their e-Health programs (eg. the Austrian participants disagreed if there is an Austrian e-Health strategy – the strategy was completed by an expert group in December 2005 [3] but has not yet been official adopted by the Ministry of Health). It was noted by several participants that the sur-

1 The conferences considered are: Nordic e-Health Conference 2006 (Copenhagen, DK), EU e-Health Conference 2006 (Malaga, ES), e-Health Benchmarking 2006 (Hall, AT), Telemed 2006 (Berlin, DE), EuroPACS 2006 (Trondheim, NO), ICICTH 2006 (Samos, GR), MIE 2006 (Maastricht, NL), GMDS 2006 (Leipzig, DE), MIR 2006 (Budapest, HU).

2 Questions: Is there a national e-Health strategy in your country? When was it formulated? Estimate for the completion of SEHR program? Trans-national interoperability considered? Basis for patient identification? Basis for health professional identification? Network infrastructure?

vey does not allow to describe the transition phase in which some projects currently are and the coexistence of regional and national programs for SEHR within one country.

General results on e-Health strategy and the SEHR program

The initial question of the survey was on the existence of a national e-Health strategy in the respective country. A majority of 83% of the answers was positive (with disagreement from the Austrians whether the current document on the e-Health strategy can be considered official, and uncertainty from the Norwegians whether there is an official e-Health strategy in their country). Only PL, PT, RO, RU were definitely negative. This result is in good agreement with [8], where it is stated that 21 out of the 25 EU member states (84%) report having adopted a national e-Health roadmap (unfortunately, [8] is not specific with regard to the countries).

The time of formulation of the e-Health strategy was given as indicated in Table 3:

Table 3 – National strategy

Time of formulation of the eHealth strategy	participants
Currently being formulated or in draft status	6 (20%)
Formulated/last updated 2006	8 (27 %)
Formulated/last updated 2005	6 (20%)
Formulated/last updated 2000-2004	7 (23%)
Formulated/last updated before 2000	1 (3%)
Uncertain	2 (7%)

The agreement amongst the participants from one nation is not very good for this question – for Austria there is only 50% agreement, with one group stating that the 2005 strategy paper is the strategy, the others considering this preliminary and seeing the strategy currently being formulated.

With respect to the existence of a national SEHR program on which they can make statements on, 57% of the participants gave a positive answer (details in table 4). This is in good agreement with [8], where electronic health records are claimed to be on the e-Health roadmaps of 14 (of 25) European member states. For Austria, we see disagreement among the participants if there is one national program or several regional programs aligned with the national strategy – and one participant reports on a research focused program.

Table 4 – SEHR program in strategy

Type of program	participants	countries
national level public sector program part of national e-health strategy	15 (43%)	AT(2), DE(2), DK, EE, FI, IL, IT, LT, SE
regional level public sector program aligned with national e-health strategy	2 (6%)	AT(2)
regional level public sector program independent of national e-health strategy	2 (6%)	RO, PL
national level private sector program	0 (0%)	
regional level private sector program	1 (3%)	PT
research focused preparatory program	8 (23%)	AT(1), CH, DE(2), GR, IT, NO(1), RU
No SEHR program	7 (20%)	CH, FR, IS, NO(4)

Also for Germany, one part of the participants makes statements on the national program (which is currently not specific about SEHR but focused on e-prescription [10]), the other on research projects. Among the participants from Norway, one reports on a research program for SEHR, whereas the others see no SEHR program in their country. The vast majority sees national level public sector SEHR programs in their countries. Private sector SEHR programs are very rare.

Table 5 – SEHR timeframe

SEHR timeframe	According to official statements	According to private opinion
2006/already available	3 (12%)	1 (4%)
2007	4 (15%)	2 (8%)
2008	5 (19%)	1 (4%)
2009	1 (4%)	5 (19%)
2010	5 (19%)	7 (27%)
2011	0 (0%)	1 (4%)
2012 or later	1 (4%)	8 (31%)
No statement	7 (27%)	1 (4%)

The high percentage of research focused programs mentioned shows that SEHR is still very much in a transitory state, with concepts still being formulated. The names of

the SEHR projects given by the participants are listed in table 6.

The timeframe for the completion of a working SEHR with advanced functionality and coverage is seen fairly sceptical by the participants, with their private opinion being far behind official statements (table 5), with the majority seeing the completion of the SEHR project beyond 2012.

Table 6 – SEHR projects

Project name	Country	inhabitants covered
RTS-Rede Telemática da Saúde	PT	150
Electronic health certificate project (preliminary)	RU	
National EPR service	FI	5 million
bIT4Health, Telematikinfrastruktur und elektronische Gesundheitskarte	DE(4)	80 million
Israel National EHR Program	IL	5 million
Estonian Digital Health Record	EE	1.4 million
National e-Health System (NESS)	LT	3.5 million
Research and development programme for electronic health record, Norwegian University of Science and Technology (NTNU)	NO(1)	
Silesian startup project for national EPR	PL	Currently 5 million (of 39 million planned)
National IT Strategy for the Health Care Service 2003-2007	DK	5 million
"Sanità Elettronica 2010" (e-Health 2010)	IT	60 million
ELGA (Elektronische Gesundheitsakte), eHI (eHealth Initiative)	AT(4)	8 millions
MediNET	RO	200.000
National patient summary	SE	9 million

The current percentage of completion of the project is generally seen to be in the very early stages (with very good agreement among participants from one nation), with only the small scale Portuguese project claiming imminent completion (Table 7). Even the representatives from Denmark, well known for its avant-garde position in e-Health and SEHR, claim only to be between 25% and 50% complete.

Table 7 – Percentage of completion

Current percentage of completion of SEHR	participants
0% - 25% (preparatory phase)	16 (61%)
25% - 50% (pilot projects)	9 (35%)
50% - 75% (full rollout)	0 (0%)
75% - 100% (finishing)	1 (4%)

Special results on the technical aspects of the SEHR programs

The question, if trans-national (especially European-level) interoperability was a concrete issue in the SEHR project was surprisingly negated by 37% of the participants (56% were positive, 7% uncertain), which shows the importance of EU initiatives to foster interoperability.

The means for patient identification are given (in very good agreement amongst the participants) in Table 8

Table 8 – Means of patient identification

Means of patient identification	participants
Patient health chipcard or identification token	9 (32%)
eGovernment citizen chipcard or identification token	1 (4%)
Unique national citizen identification number	11 (39%)
Unique national patient identification number	3 (11%)
Social insurance number	0 (0,0%)
Master Patient Index systems for the federation of patient data between healthcare organizations	0 (0,0%)
Not decided yet	3 (11%)
Uncertain	1 (4%)

National citizen identification numbers are the top means of identification, with patient chipcards coming next (also in [8], it is stated that health cards are on the roadmaps of 10 of 25 European countries). The social insurance number is nowhere used for patient identification.

The means to identify health professionals are given in table 9.

Table 9 – Means of health professional identification

Means of health professional identification	participants
Health professional card	14 (52%)
Identification token stored on some other medium	0 (0%)
User accounts maintained in the SEHR or connected systems	7 (26%)
Not decided yet	5 (18%)
Uncertain	1 (4%)

The health professional card is clearly predominant, but also in national projects (Estonia and Lithuania), user accounts maintained in the SEHR or connected systems serve as means for user identification (and access control).

With regard to the network infrastructure and protocols used for access to the SEHR, the Internet protocol is clearly undisputed. A secluded intranet is the prime choice, but also encrypted connections via the public Internet are considered (see table 10).

Table 10 – Type of network infrastructure

Type of network infrastructure	participants
Secluded Intranet for the Healthcare sector based on Internet Protocol	13 (52%)
Secluded network for the Healthcare sector based on some other protocol	0 (0%)
Public Internet with appropriate encryption	9 (36%)
Uncertain	3 (12%)

For the additional services that are to be offered together with the SEHR for patients and health professionals, the results are shown in figure 1.

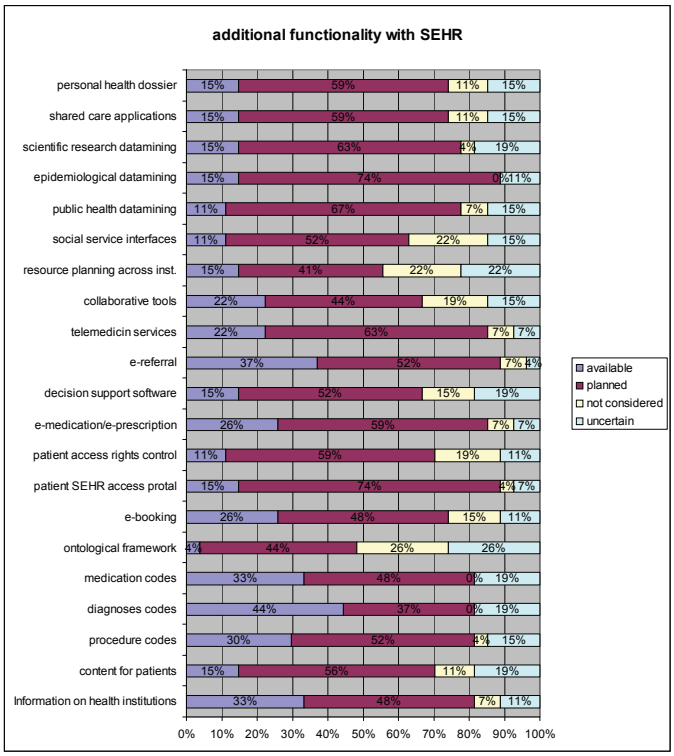

Figure 1 – Additional services

Among the currently available functionalities, common nomenclatures for diagnoses, medication and procedures, e-medication/e-prescription and e-booking along with information on healthcare institutions are predominant. Patient portals are mostly being planned, with various participants stating that functionality for patients to control access rights to their health record data is not considered. Complete ontological frameworks are considered least important.

For the central question for this survey, the design of the SEHR architecture, the participants were given the choice between 5 different designs, ranging from a completely centralized approach for the storage of all SEHR data to completely unfederated decentralized SEHR:

- Completely central architecture (with limited number of national data centres): Central Patient Index; Central Metadata Index and Patient Summary Data Repository; Central Repository for full SEHR data
- Mostly central architecture (all core data stored in limited number of national centres): Central Patient Index; Central Metadata Index and Patient Summary Data Repository; Decentral Repository for full SEHR data
- Mostly decentral federated architecture: Central Patient Index; Decentral Metadata Index and Patient Summary Data Repository; Decentral Repository for full SEHR data

- Completely decentral federated architecture (federation of RHIO's with cross community data access): Decentral Patient Indices; Decentral Metadata Index and Patient Summary Data Repository; Decentral Repository for full SEHR data
- Completely decentral unfederated architecture (unfederated RHIOs): Decentral Patient Indices without cross enterprise federation; Decentral Metadata Index and Patient Summary Data Repository; Decentral Repository for full SEHR data

The results found are given in Table 11:

Table 11 – Architecture type

Architecture type	participants	countries
Compl. central architecture	1 (4%)	FI
Mostly central architecture	6 (22%)	AT(2),DK, EE,GR,LT
Mostly decentral federated architecture	9 (33%)	AT(3),CH,DE,EE,RO,SE
Completely decentral federated architecture	3 (11%)	DE,IT(2)
Completely decentral unfederated architecture	1 (4%)	IL
Other/not yet decided	5 (19%)	DE,DK,NO, PL,RU
Uncertain	2 (7%)	NO,PT

Only one participant from Finland sees the national SEHR effort directed towards an all central architecture. The mostly central and mostly decentral architectures prevail – for pragmatic reasons (eg. the amount of actual EHR data that would have otherwise to be stored centrally).

Table 12 – Regulation for data in SEHR

Regulation for data in SEHR	Participants
National regulation exists	4 (15%)
Regional regulation exists	2 (7%)
National regulation is planned	12 (44%)
Regional regulation is planned	1 (4%)
No regulations are planned - agreements between healthcare will do	5 (19%)
Uncertain	3 (11%)

The situation with not yet final specifications for SEHR architectures has its impact on the disagreement between the participants (in Austria, the e-Health strategy prepared by the e-Health Initiative favours a mostly decentral architecture, whereas the preliminary results from a government commissioned feasibility study tend towards a mostly central architecture).

Regarding the question, whether there are regulations on what data items are to be published into the SEHR, the participants gave the answers in table 12.

The data items considered to be available via the SEHR (currently or in the future) were named to be:

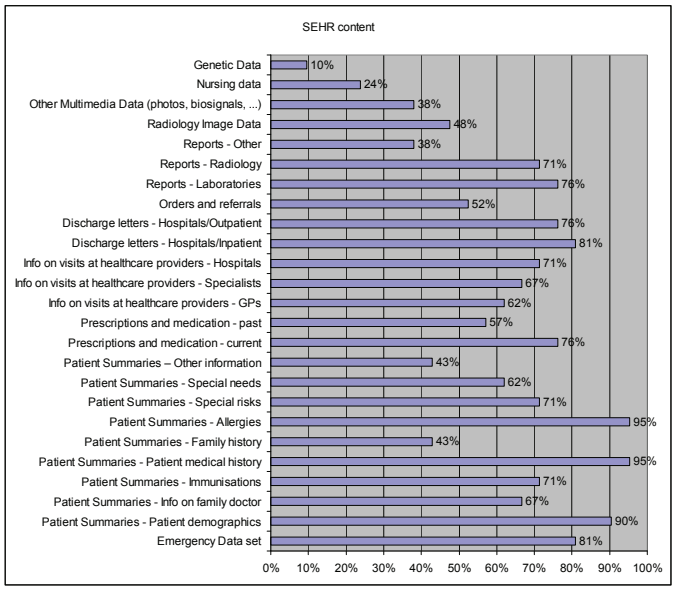

Figure 2 –Data items in SEHR

For the Israeli program, it was mentioned that a unified discharge summary based on HL7 V3 CDA was considered and confidential information on sexual abuse might also be part of the SEHR.

On the question regarding the standards and technical frameworks considered for the content and the communication of the SEHR, the participants gave the priorities listed in Figure 3. The participants see a clear prevalence of HL7 CDA (eg. over CEN 13606) for the SEHR content. IHE XDS is also very popular as a set of protocols for access to SEHR data – but only slightly in advance over CEN EN 13606 EHRCOM, in which's scope transmission of healthcare information is also contained. Even though CEN EN 13606 will be a harmonized European standard once completed, the HL7 CDA as ANSI and ISO standard has good reception since its adoption by industry is much better. The good acceptance of ICD and ICMP does not come as a surprise. SNOMED CT is very well considered with 42 %. The popularity of DICOM can also be seen. For Denmark, it was pointed out that the national B-EPR standard which is akin to CEN 13606 is being used. For Italy, the compliance of the SEHR with the "Sistema Pubblico di Cooperazione (SPCoop, Public Cooperation System)" as a national standard was noted. This compilation gives an impression of the importance of various standards, technical frameworks and nomenclatures in the eyes of experts in the field. Since in most cases, the SEHR programs are

still in their very early stages with room for adaptation driven by the national experts, possible directions for the adoption of standards can be seen, where there are no binding regulations yet.

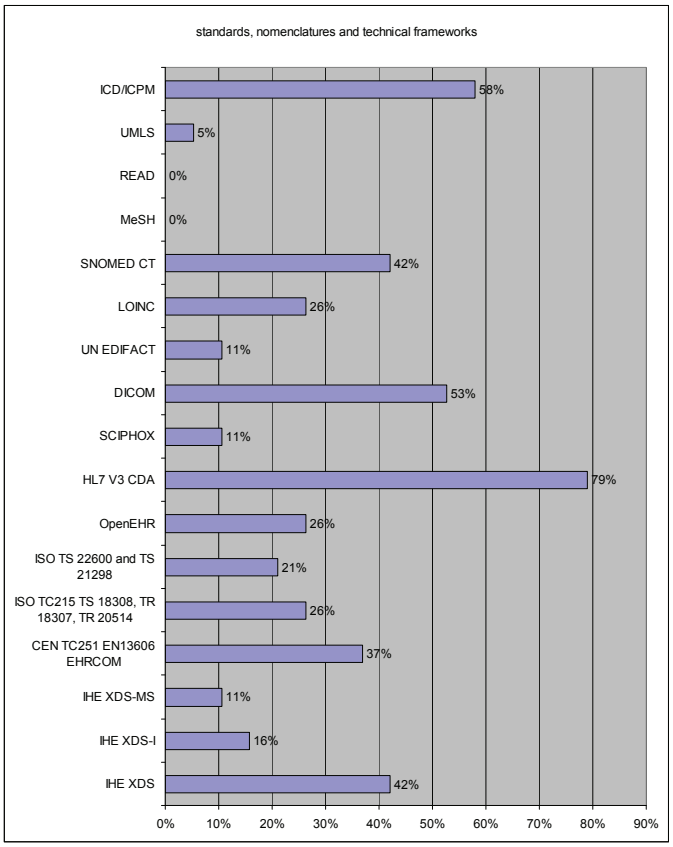

Figure 3 –Standards and technical framework

Conclusion

Contrary to the approach in [9], not national governments or e-Health competence centres were approached with questions on the technical aspects of the national SEHR programs but experts working on these projects. This brings in a certain bias from the individual viewpoints of these experts, but also "official" statements by government institutions (Ministry of Health, national competence centres) do not have to reflect the situation indisputably – apart from being very hard to obtain on a technical level. Looking on the agreement between multiple participants from one nation, it can be seen that there is generally good consensus on the main technical issues. Most disagreement comes from early stage of the programs and transitory phase from pilots and basic infrastructure to full SEHRs. The SEHR programs are in an early stage where specifications are not finalized and still subject to change. Research and pilot projects, that have in some cases been initiated more than a decade ago, are present in some countries giving directions for how pervasive solutions could work and have to be incorporated into future infrastructures. Regional and national activities coexist to form together the SEHR functionality. National approaches are fairly different across Europe and trans-national interoperability is not seen as a core issue. Industry standards and initiatives (HL7 CDA, DICOM, IHE) are most influential amongst the experts and thus have the potential to lead to basically similar and interoperable architectures for SEHR across Europe. The European standardization effort (CEN EN 13606) is not seen as so important. For the SEHR architecture, most participants foresee a mostly decentralized design with central patient index, but distributed metadata registries and data repositories. The Internet protocol is undisputed as basic transport medium – where secluded intranets as platforms for the utilization of the SEHR are predominant over encrypted communication via the public Internet. Chipcards are seen as one of the main means for patient identification for the SEHR, and health professional cards are rated top for identification of healthcare professions. The timeframe for completion of the SEHR programs is seen by most experts in their private opinion more sceptical than in the official statements, foreseeing completion mainly in a timeline 2010 or later.

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