Core European eDocuments

A dynamic internet based Patient Summary for emergency and unexpected care

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EHTEL - European Health Telematics Association (Europe)
NICTIZ - The Dutch National ICT Institute for Healthcare (The Netherlands)
CARELINK - Swedish Network for Communication in Health Care (Sweden)
KITH - Information Technology for Health and Welfare (Norway)
STAKES - National Research and Development Centre for Welfare and Health (Finland)
EDISANTE - French Association for Healthcare Data Interchange (France)
IHC/NHS - Informing Healthcare (Wales)
MEDTEL - National Association for Telematic in Medicine (Czech Republic)
IZIP - Internet Access to Patient Healthcare Information (Czech Republic)
MEDCOM - Danish Health Care Network (Denmark)
ZZSZ - Health Insurance of Slovenia (Slovenia)
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1 “Core European eDocuments” is a proposal for a start-up web-based European Patient Summary made in a pragmatic and straight-forward way. The proposal is written by MedCom in close cooperation with “the ELO group” of national implementation organisations in EHTEL. The CORE-project is open to all EU-member states and aims to support further collaboration between national organisations and health authorities already implementing interoperability in health. The proposal covers a part of the Patient Summary described in the EU report “Connected Health - Quality and safety for European Citizens”. EU 12-09-2006.
**Executive Summary**

During the last 15 years the European commission and the EU member states have promoted regional, national and trans-national interoperability of secure eHealth services as part of the eEurope programmes.

The purposes have been and still are to provide a citizen centred care to an increasingly mobile and also aging population in need of a continuum of care services irrespective of time and location and to secure access to a wider market for European vendors. Most recently this has been spelt out in the commission’s document “Connected Health” of 2006 reflecting the work of the “i2010 subgroup on eHealth” and the “eHealth stakeholders group”.

The EHTEL group of national eHealth competence centres has been working on a collaborative project open to all EU-member states that are actually implementing eHealth interoperability in their respective countries.

The national competence centres having expressed their intention to participate already at this moment are:

- NICTIZ - The Dutch National ICT Institute for Healthcare (The Netherlands)
- CARELINK - Swedish Network for Communication in Health Care (Sweden)
- KITH - Information Technology for Health and Welfare” (Norway)
- STAKES - National Research and Development Centre for Welfare and Health (Finland)
- EDISANTE - French Association for Healthcare Data Interchange (France)
- IHC/NHS - Informing Healthcare (Wales)
- MEDTEL - National Association for Telematic in Medicine (Czech Republic)
- IZIP - Internet Access to Patient Healthcare Information (Czech Republic)
- MEDCOM - Danish Health Care Network (Denmark)
- ZZZS - Health Insurance of Slovenia (Slovenia)

It is important to the National Competence Centres that the project will be brought in line with the implementation of the i2010 Action Plan agreed by the i2010 subgroup on eHealth and the eHealth stakeholders group.

The goal of “Core European” is to fulfil two important clinical needs:

- To make basic patient information available to care providers and patients in the event of unexpected illness e.g. during travelling or in emergency situations and
- To act as a pointer to patient data and health care contacts in a fragmented health sector.

“Core European” would give doctors and patients on-line Internet web access to a dynamic summary of basic patient data. The Patient Summary is updated on demand with real-life patient data, already communicated on paper or electronically between the participating health institutions such as discharge letters, prescriptions, referrals and lab reports. This
automated data collection secures immediate and reliable data in the internet based Patient Summary.

Core European

- Patient Summary
  For unexpected and emergency care

- eDocuments
  For daily routine communication

Conceptually, the project builds on the Danish MedCom message experiences and the Swedish Patient Summary - but now in a European framework.

Trying not to re-invent the wheel, the CORE project takes its outset in the clinical content and structure of the Danish e-messages and give Internet access to this information in a Patient Summary inspired by the Swedish work. This pragmatic and straight-forward approach makes it realistic to create a real-life, cross-border Core European Patient Summary running in few years.

The project has three phases:

- **Phase 1: Create Core European eDocuments**
  The creation of a set of Core European eDocuments is done in cooperation with the pilot projects in each of the participating countries. Taking the outset in an existing proposal for a Nordic set of clinical documents, a European set of Core Documents is created by the participating countries. The result can be documented in several international standards, e.g. HL7, W3CXML or CEN making it possible to convert and choose between different standards as used in the participating countries.

- **Phase 2: Demo in large scale pilot**
  The set of European eDocuments is tested large scale in real (but anonymous) patient communications. In each participating country a large pilot project is set up. In the national pilot a hospital, cooperating primary clinics, a radiology clinic, a laboratory and pharmacies may participate. Reusing the existing pilot communication of prescriptions, lab-results and discharge letters it would be possible to update the European Patient Summary instantaneously and automatically from the local pilot IT systems. To avoid legal, privacy and security problems, all patient data are made anonymous in the demo phase - making it impossible to track data to the actual patients.
Phase 3: Disseminate Core European eDocuments nationally and across interested countries.

After the pilots, the validated European eDocuments and the validated Core Patient Summary may be disseminated nationally and across borders in Europe. National health authorities and competence centres should preferably play an important role in the dissemination process.

“Core European” might contribute to the clinical content of national or regional Patient Summaries, e.g. as the communication part of the Swedish Patient Summary.

“Core European” might be used as national eMessages for communication of lab-results, discharge letters or prescriptions.

“Core European” might be communicated by means of different national infrastructures, for instance health cards or in secure health nets.

“Core European” might be converted between different international standards used in the different European countries.

In the dissemination phase cross regional, national and even international communication of real patient data is started – taking into account the national differences in legal, organisational and technological strategies and needs.

The CORE project will result in

1. A running web-based “European Patient Summary” for clinical communication - giving cross European access to patient data from real-life pilot projects in several European countries.

2. A set of “Core European eDocuments” - building on best practices and adjusted to clinical habits in the participating member states.

3. An opportunity for member states and regions afterwards to use Core European eDocuments in their own national IT strategies - using the national IT infrastructures (e.g. “The Spine” of England, The Swedish “Patient Index” or the “Switch Point” of the Netherlands) and their own national syntax standards (e.g. HL7, W3CXML, CEN, HISA or EDI) but still being able to communicate across borders.

4. An opportunity for participating and other IT industry to develop and sell regional or national Patient Summaries and eDocument “plug-and-play” and “off-the-shelf” products to their customers.
1 The EU rationale for health IT Interoperability

1.1 EU actions for eHealth Interoperability

Following the “Lisbon Plan” of year 2000 and the eEurope action plan of 2002 eHealth has been key in the EU framework programmes for research and technical developments (FPs) for more than 15 years always highlighting the necessity of interoperability at the regional, national and transnational level both in the interest of the citizens and of the vendors needing a market of critical mass to become profitable.

This view was paving the way for member states’ inclusion of eHealth in the eEurope 2005 Action Plan: “An Information Society for All” aiming at providing services, applications and content for eGovernment, eLearning, eHealth services and a dynamic e-business environment on interoperable broadband infrastructures.

Recently, the EU Commission issued the next plan: “i2010 – A European Information Society for Growth and Development” setting three targets: 1. A single European information space, 2. Innovation and investment in research and 3. Inclusion, Better Public Services and Quality of Life. eHealth is explicitly part of the latter but may also come under other headings.

The plans were endorsed by health ministers at the first health ministerial conference in Brussels in 2003 and reconfirmed at similar subsequent events in 2004, 2005 and recently in Malaga in 2006.

The free movement of not only capital and goods but also citizens and services maintained by the treaty has led to certain claims from citizens that it would be their rights to have the health service they wanted from any EU country at the conditions prevailing in their home country.

Some notable rulings by the European court of justice have protected the citizens’ rights accordingly, but at the same time admitting the individual member states their right to regulate the conditions under which such right are exploited.

Already in 2004 the EU commission issued three communications directly relating to eHealth and the citizens’ rights to health services in other member states:

1. “Follow-up to the high level reflection process on patient mobility and health care developments in the European Union” Com (2004) 301. It envisages release of information clarifying the rights for citizens to health care services abroad and an


effort to produce simpler and transparent rules for the recognition of professionals’ qualifications and the use of eHealth abroad.

2. “e-Health – making healthcare better for European citizens: An action plan for a European e-health Area” (Com2004 356), which the council of ministers took favourably note of same year. The action plan is focussed around two issues: addressing common challenges and successful implementation through pilot projects.

3. “Modernising social protection for the development of high-quality, accessible and sustainable health care and long-term care: support for the national strategies using the “open method of coordination” (COM2004 304). Referring to the two other communications it suggests framework for coordination of member states' endeavours to provide a global strategy for health care systems to contribute to social cohesion and total employment. The communication emphasizes that the joint objectives of all stakeholders are universal access, fairness and solidarity. It suggests indicators to be identified and a report delivered in 2007.

As a consequence of this conformity of member states’ opinions two groups have been established: “The i2010 subgroup on eHealth” and the “eHealth Stakeholder Group” with the vision to provide a continuum of care for citizens and a favourable competition situation for European vendors in a knowledge-based society. This vision is made crystal clear in the recent DG INFSO publication: “Connected Health” of September 2006. That document and the work leading to its creation is one of the rationale for this proposal on “Core European eDocuments” for the creation of patient summaries.

1.2 European Mobility and Demography
Looking at different sources a qualified guess would be that the interchange of patients between countries is approximately 0.5 to 1%, while it is may be 10 to 15% between regions within a country.

As borders fall in Europe, the mobile citizen, is now, more than ever before, working, vacationing, or retiring in a country other than his native one. The necessity for trans-national healthcare is increasing, together with the need for interoperability between the healthcare systems, health records, etc. Trans-national eHealth services could well serve these needs, provided the systems can work together across national borders. The Euro-citizen of the future will have many more trans-national needs both within Europe and even global needs across the world, many needs potentially well served with the medium of eHealth if it can be interconnected and interoperable across regional and national borders.

The changing demography of Europe means that the percent of aging patients will be increasing; coupled with their better financial status (compared with the previous generation), and increased mobility, mobile retirees who could be well served with eCare services across national borders, will also be increasing.
2 Core European eDocuments

2.1 Project goal
In all European countries, there is a frequent, rapidly growing daily routine communication of prescriptions, laboratory results, discharge letters, referrals and test-results between hospitals, clinics, specialists, pharmacies, labs and homecare providers.

Today, this paper documents are handled in the IT systems used in hospitals, primary clinics and laboratories, and then printed and sent by post.

The goal of “Core European eDocuments” - The CORE Project – is to make this basic patient information available to care providers and to patients in the event of unexpected illness e.g. during travelling or in emergency situations and to act as a pointer to patient data and health care contacts in a fragmented health sector.

This will be done

- creating a European set of clinical eDocuments for the most frequent messages communicated between the different health sectors and institutions - and
- give Internet access to this data for citizens and health professionals via an web-based European Patient Summary.

Core European

- Patient Summary
  For unexpected and emergency care

- eDocuments
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The European Patient Summary might be used for true European cross-border communication of clinical information - supporting free mobility of patients from Sweden to Spain and from Portugal to Greece.

Besides, Core European eDocuments can be used for internal health communication in each of the participating countries in many ways. Core European eDocuments would be equally usable and independent of which national IT strategy, IT infrastructure and syntax standards are used in the country.
2.2 Combining Danish MedCom messages and Swedish Patient Summary

Trying not to reinventing the wheel, the CORE project takes its outset in the clinical content and structure from Danish MedCom e-messages and gives Internet access to this information in a Patient Summary inspired by the Swedish Patient Summary.

- In Denmark, “MedCom” has since 1994 implemented and expanded the electronic communication of the most frequently needed clinical information between the different health care institutions by means of standardized, structured eMessages. The MedCom communication covers around 25 different documents including prescriptions, discharge-letters, referrals and lab-results. Today, 2.5 million messages are exchanged electronically each month - more than 100 millions eMessages since the beginning. The MedCom documents were developed in pilot projects and structured in the same way as they were used in writing in clinical practice before they were transmitted electronically. In 2002 a similar Nordic set of eDocuments were developed by the five Nordic countries, called “Good Nordic EDI-messages”.

Swedish Patient Summary
Web - access to medical documents

- In Sweden, “Carelink” has developed a national patient Summary, now running in pilot projects. The Swedish Patient Summary is an Internet “viewer”, getting access to patient data across-borders between regions.

The Swedish Patient Summary contains three parts:

- Basic patient data like ID, name and address and name and contact data on relatives and own doctor
- Prescribed medication
- Clinical documents like discharge letters, lab-reports, diagnoses and radiology results
The Swedish Summary is organised similarly to an ordinary e-mail system. Each of the clinical documents is shown as “incoming mail” - making it possible for the user to select and read the document in the same manner as when reading ordinary text emails. Editing contact information and organising clinical documents might be done manually by the patient or by an authorized health professional. This well known user-interface makes it easy to use even for new users.

Combining the MedCom message experiences and the Swedish Patient Summary makes it realistic to create a pragmatic and straight-forward European Patient Summary.

| Core data elements are located inside medical documents. |
| Core data can be extracted from these documents, for example to produce various listings: |
| Diagnoses |
| Medications |
| Risk data |
| Core data can be “recycled” to be included in new documents, for example referrals, doctor’s orders and medical certificates. |

Dr. J Komulainen, University of Kuopio, Finland

Such a Patient Summary would

- Be automatically updated with real-life data
  The CORE project is re-using the existing clinical communication in the pilot projects. Due to this, the summary are updated instant and automatically with real data. No new work and no retyping are needed. Both basic data and clinical information in the patient summaries may be extracted automatically from the existing clinical IT systems in the pilots or extracted from an existing, updated central database.

- Be built on ten years of clinical practice - adjusted to new countries
  The clinical data content and data structure in the Patient Summary may be defined building on more than 10 years of practical experience from Danish MedCom communication - adjusting these eDocuments to clinical practice in all the countries participating in the CORE project.

- Be flexible in use and gradually more and more integrated
  Using eDocuments as “brick stones” for the clinical information makes a flexible development possible where the clinical content differs from country to country and besides data might be gradually integrated more and more in the participating IT systems. When fully integrated, the Patient Summary is used as a “switch-point” between different IT systems.
2.3 A Dynamic Patient Summary for emergency care

As mentioned earlier, there is a widespread tradition for exchanging clinical information between different health institutions in Europe. This communication is mainly done by means of well-known paper based forms like discharge letters, referrals, lab-results, prescriptions and radiology reports.

The clinical documents contains

- Document identifying information like “to” and “from”
- Patient identifying information and contacts
- Basic health information like allergy
- Insurance and financial information
- Diagnoses, anamnesis and reasons for referral
- Prescribed medication
- Lab-results and radiology results

To day, the mentioned documents are often handled and stored by means of existing IT systems already used in the health institutions and afterwards printed and sent to the receiving health institutions.

This European tradition of sharing clinical information between different health institutions is re-used in the CORE Project making it possible to update the patient Summary instantly and automatically.

Clinical Datasets

- Core European eDocument data are extracted from existing medical documents
- US Continuous Care Record (CCR) are defined as a general referral document
- Emergency data is mainly a part of both datasets
- The different data sets have a large overlap

Sharing patient information across organisational borders is not as widespread in USA as in Europe. Instead a dataset called “CCR – Continuity of Care Record” are defined by the American standardisation body ASTM for referring patients cross health institutions.
The CCR dataset contains the most relevant information about a patient’s healthcare divided in these six parts:

- Document identifying information like “to” and “from” and reason for referral
- Patient identifying information
- Insurance and financial Information
- Health status of patient like diagnoses, allergies, current medication, immunization, vital signs, lab-results and procedures.
- Care Documentation in text
- Care Plan Recommendation

As can be seen, the clinical content in CORE and CCR datasets are quite similar – both mirroring the clinical information needs in typically user cases.

In emergency situations or when caring a new, unknown patient, it would be relevant to have a summary of the patient’s actual health status including allergy and diagnoses and medication. In the CORE project a more precise dataset for emergency is developed, extracted from the eDocuments and stored as a part of the Patient Summary basic information.

Besides being accessible on the Patient Summary, the emergency data, basic patient data and data sets from the other medical document may be communicated on health cards and local networks.
2.4 The CORE Project’s three Phases

The project consists of three phases:

- In the first **creation phase**, the Core European eDocuments are developed taking into account the different needs in the participating countries.
- In the second **pilot demo phase** real, but anonymous patient data is extracted from nationally pilot projects and published on a web based Core European Patient Summary.
- In the last **dissemination phase** the solution is modified to nationally and regional conditions and real patient data are used.

**Phase 1: Create Core European eDocuments**

The creation of a complete set of Core European eDocuments is done in cooperation with pilot projects in each of the participating countries. To prevent reinventing the wheel, the outset of this work is taken in the Danish MedCom messages - or more precisely in an existing set of MedCom documents adjusted to use in the Nordic countries (“Good Nordic EDI messages”, 2002).

In the pilot projects local used templates for prescriptions, discharge letters, lab-results etc. are compared - field by field - with the Nordic templates. Taken the differences between the countries into consideration, a common new set of European structured documents are created.

Finally, the developed set of Core European eDocuments might be documented in several international standards, for example in HL7, W3CXML, CEN, HISA or EDI making it possible to convert between the different standards already in use in Europe.

**Phase 2: Demo in anonymous large scale pilots**

In the Demo phase large scale pilots in the participating countries are set up – and a web based European Patient Summary are developed.

In each participating country one or more pilot projects are set up. In each pilot a hospital, some cooperating primary clinics, a radiology clinic, a laboratory and some pharmacies may participate. Reusing the existing paper based pilot communication of prescriptions, lab-results and discharge letters it would be possible to update the European Patient Summary Demo instantanously and automatically from the pilot IT systems. The participating health institutions and the selected messages might differ from one pilot to the other depending on the actual needs in the country. From the pilot IT systems, data is extracted and delivered to the Patient Summary Demo.

To avoid legal, privacy and security problems, all patient data is made pseudo anonymous in the demo phase - making it impossible to track data to the actual patients.
Large Scale Pilot

- Same data presentation from all countries
- Automatically, immediately and real-life data
- Flexible
- WS & eMessage technique
- VPN encrypted
- SSL encryption to citizens
- Anonymous data in the demo phase
- All pilots do ePrescription!

From the local pilot IT systems, data is extracted and delivered to the Core European Patient Summary. All citizens would be able to access their data using standard, secure internet access.

Depending on the situation and IT strategy in the participating countries, data might be extracted directly from pilot IT systems, from central databases or from existing Patient Summaries.

Phase 3: Disseminate Core European

After the pilots, the validated European eDocuments and Patient Summary are adjusted and gradually disseminated nationally and across borders in Europe. National health authorities and competence centres should preferably play an important role in the dissemination process.

Core European

- might contribute to the clinical content of national patients summaries, e.g. as the communication part of the Swedish Patient Summary.
- might be used as national eMessages for communication of lab-results, discharge letters or prescriptions.
- might be communicated by means of national infrastructures, for instance health cards or in secure health nets.
- might be converted between different international standards used in the different European countries.
The pilots are an important part of the project and contribute in all project stages:

- In first phase, pilot health professionals compare actual paper letters already in use in the country with a drafted unified and common proposal per type of document, going to be used later in all pilots.

- In the second phase, extraction of Core European eDocuments to the European Patient Summary is implemented as a module of the existing IT systems already in use by the health institutions. For this reason all participating health institutions must have clinical IT systems in full operation and the vendors of these systems must be involved in the project, integrating the communication modules as applications in their IT systems.

After the project, the participating IT vendors may sell and disseminate the developed solutions to other customers in the country.

In this process the pilot set-up is going to be changed to become part of national IT strategies following the infrastructure and standards used in the actual country.

2.5 Results
The CORE project will result in

1. A running web-based “European Patient Summary Demo” for clinical communication - giving cross European access to patient data from real-life pilot projects in several European countries.

2. A set of “Core European eDocuments” - building on best practices and adjusted to clinical habits in the participating member states.

3. An opportunity for member states afterwards to use Core European eDocuments in their own national IT strategies - using the national IT infrastructures (e.g. “The Spine” of England, The Swedish “Patient Index” or the “Switch Point” of the Netherlands) and their own national syntax standards (e.g. HL7, W3CXML, CEN, HISA, CCR or EDI) but still being able to communicate across borders.

4. An opportunity for participating and other health-IT industries to develop regional or national Patient Summaries and to sell eDocument “plug-and-play” and “off-the-shelf” products to their customers.