Peer Review Workshop:
Benchmarking and evaluation of e-Health deployment in Sweden

Preamble

The purpose of this so-called "Peer Review Workshop" was to provide the Swedish Association of Local Authorities and Regions (SALAR) and more particularly the National Centre for Coordination of e-Health (NCCEH) with input from international senior eHealth experts for the preparation of the new work programme aiming at further deploying the "Swedish strategy for eHealth – safe and accessible information in health and social care".

The team of international senior experts who contributed to the meeting has been build by EHTEL and was made of 10 experts coming from Austria, Denmark, England, Finland, France, Germany, Italy, Belgium and Switzerland. The participants on the Swedish side were 20 in total, but some only attended a part of the workshop.

One has to note that the term "peer review" is to be understood not in its academic meaning, but in a broader sense: a review of deployment progresses and issues by peers.

One has to further note that these experts were speaking on their own behalf only, although some of them may be sitting as official representative of their country in formal EU Working Groups. The list and contact details of the participating experts are enclosed, in annex of this document.

This report is written in the context and provides only information complementary to the documentation material that was provided in advance of the meeting and the presentations used during the meeting.

All files are available for download at the following URL (do not try to double-click on the address, but copy exactly to your browser): **ftp://peersweden2009:arlanDIA@ehtel.org**. In case a dedicated FTP client is used:
FTP server = ftp.ehtel.org, username = peersweden2009, password = arlanDIA

0 Welcome and Introduction

After a warm welcome by Gösta Malmer of SALAR - NCCEH and a roll call of all participants the workshop theme is introduced by Susanne Bergman, representing the Ministry for Health and Social Affairs of Sweden. She provided a short introduction to the National Strategy for e-Health and the role of the various actors for its implementation.

Following the introduction of Susanne Bergman, Gösta Malmer introduces Mats Larson of Caritea AB, who takes then over as moderator of the peer review workshop.

1 Architecture including information structure and semantics

The architecture item has been introduced by Nils Schönström, Clinical Architect, MD, who has been followed-up by Karl-Henrik Lundell, Medical Director at SALAR, and then by Lotti Barlow from The National Board of Health and Welfare.

The main outcomes of the discussions which followed are summarised in the below paragraphs.

1.1 Which data needs to be structured? Which one should remain unstructured?

Out of the discussion on clinical documentation and interdisciplinary language quickly the question emerges which clinical data needs to be structured and which one may remain in – or even needs to be in – free text. One way to make the distinction is that free text is useful for personal use by the health professional and for communication within one health professional domain while structured data is more appropriate as soon as it has to be more widely communicated (i.e. when information is passing through an interface, from one domain to another).

It was noted that because of the long established practice of health professionals, much less terms than those in complex medical nomenclatures like SNOMED CT could be needed for communications between health professionals. Clinical pathways could be a means to assess what is to be communicated.

On that basis, one could conclude that the focus should/could be put on the data that needs to be shared. The approach could therefore be the following: free text for an individual treatment for an individual patient, structured information for the purposes of the health care system. It was also noted that SNOMED CT is not the only source of structured information. While ICD-10 is the reference classification for health statistics and accounting, many activities in health and social care in Sweden refer to the ICF (International Classification of Functioning, Disability and Health). Which system has to be used for structuring which data? That work has still to be done.

1.2 Can SNOMED actually be used in clinical practice?

Denmark has completed the translation of SNOMED CT in Danish and the usability in clinical practice question remains open. Maybe it would have been better first to start with some practical applications instead of forcing the full translation.

SNOMED CT is of course fully useful in the Pathology domain and some hospital areas in DK start to use it, but the added value of SNOMED CT in the primary care, clinical and medication areas has still to be clarified. It was furthermore recognised that the first and most important question still to address is the inter-relationships with ICD-10 and particularly the DRG system. The financial aspect is indeed an essential one.

The attention was also drawn on the fact legacy systems may not be able to support SNOMED CT and an interim solutions will be needed for a while.

One noted also that the value of SNOMED CT is also recognised in the context of Quality Management Systems.

1.3 The Swedish approach to prepare semantic interoperability

An exchange of view took place at the end of the discussion on the "theoretical modelling" work as it was noted that the complexity of the real world was very high, taking in particular into account the multi-morbidity element and also the fact that a care process may need to be changed while being applied.

It was recognised that each health problem has its own process and data need for its resolution and that a lot is still to be done in interconnecting different processes.

2 Technical infrastructure (communication, directories, security cards)

That subject has been introduced by Peter Alvinsson, CIO County Council of Kalmar and Christian Elmehagen, CIO of Sjukvårdsrådgivningen AB.

2.1 Is a dedicated secure health network to be preferred to the Internet?

To that question, it was answered that, in England, the security is more and more implemented at application level. In Austria too, while Health Professionals are connected through a secure network, so that security depends as less as possible from the behaviour of individuals, there are thoughts about implementing security at the application level to enable using the Internet.

On the contrary, DK is moving away from the Internet, dedicated cables are now prepared for secure connections.

One can therefore consider that there is currently no single answer to that question. However additional factors have been mentioned which are important such as the reliability of the systems etc. The systems must be quick enough, easy to use and there must be backup solutions!

2.2 What is the business value for deploying smart cards?

The group has noted that a preliminary distinction had to be made when discussing about cards:

- ⇨ Patients/Citizens/Insured cards needs to be distinguished from Health Professionals cards
- ⇨ Patients/Citizens/Insured cards are facing different deployment context, depending from the social security system they are in (insurance/Bismarck-based or residence/Beveridge-based)
- ⇨ Health Professionals cards are more and more deployed, even in countries without citizen cards, in order to enforce privacy in the context of eHealth services.

In Austria and in France, the business value to deploy patients/insured cards was obvious: replacing the processing of administrative paper forms by electronic exchange of data.

In the views of the group, raising the business value of smart cards is not the right question. In England, smart cards are today seen as a pre-requisite for deploying eHealth services and business values appears only when deploying these services.

To the question “Is a smart card needed to ensure privacy?” It has been answered that when an application requires strong authentication, then smart cards are the best solution while, when the needs are limited to identifying the person, alternative solutions should be considered. It was however noted that currently, there were not so many applications which require strong authentication.

The experience in France has demonstrated that deploying smart cards for health professionals is more difficult in hospital environments because this will affect the whole identification management system of each hospital.

It was also noted that sometime/often, the choice to go for smart cards is the result of a political decision, but also people are acquainted with a smart card as a physical token and this contributes to building trust. It could therefore be considered that this is more a perception issue than a technical one. Several participants noted however that smart cards were still to be considered as a reasonable and ongoing trend, in particular when single sign-on services are to be implemented, even if expensive to maintain.

3 Services for identification, role- and access management

The subject has been introduced by Thomas Engelmark, Senior Project Manager in Sjukvårdsrådgivningen AB.

3.1 Attribute management

The key importance of the management of attributes, the basis for access authorisation, has been underlined. This is indeed a responsibility and even liability issue, but also an organisational and operational one: how far are the organisations responsible for managing these attributes technically capable to contribute to operational activities of BIF?

3.2 Care relationship and patient consent

The respective role of the care relationship mechanism and the patient consent one has been subject to some explanations for the purpose of the international experts and it was suggested that an English translation of the patient consent was circulated.

The existence of an IHE profile on patient consent has been mentioned, but it was concluded that it was not suitable in an EH/EMR context because it was document-based.

Denmark reported having a similar regulation, but explained that according to the Danish perception of privacy, there is no issue around the fact that prescriptions can be seen by every doctor that treat the patient and those cannot be blocked.

The patient consent mechanism deployed in the early sites in England was complex, and was difficult to explain to the public. This led the authorities to consider its simplification, at least to give time to the population to understand the proposals. On that basis, the opt-out approach is therefore seen as more appropriate.

While acknowledging that privacy is to some extent a cultural issue, it has also been noted that the size of the country/region where eHealth services are being deployed may also have an impact: Wales and Scotland appear to have traditions of trust not so evident in England.

It came also out of the discussion that while privacy is a key factor, another one is effectiveness and the right balance needs to be found between the two of them.

3.3 Using log files for protecting privacy

There was a recent case in Scotland, where access to personal data are being logged, in which a health professional abused their right to access patient data. While some were considering that informing the patient that his/her privacy may have been damaged could create troubles in the population, it appears that, on the contrary, this has reinforced trust by demonstrating how far privacy has been monitored, and breaches acted upon.

4 National Patient ~~Summary~~ Overview

The subject has been introduced by Ante Grubbström, CIO, County Council of Sörmland.

The National Patient Summary (NPÖ – better translated as National Patient Overview) is intended to facilitate – for health professionals – the access to important information on patients who have received care from any care provider in Sweden. An English-speaking information – downloaded from the website www.npö.nu – has been added to the peer review documentation at ftp.ehtel.org.

Together with the patient overview, a new integrated pictogram for signalling adverse events, drug allergies etc. has been developed that is suggested for European / international use. The members of the international team are kindly invited to consider this.

4.1 A dedicated patient summary dataset or full access to patient primary data?

As opposed to providing patients/citizens only access to limited data, within a current Danish project, patients can get – using their personal digital certificate – access to all their patient records in all Danish hospitals. This access is facilitated by a central index, yet without copying data. Still there is some debate in Denmark around this project, i.e. whether patients need more guidance.

Finland will build a National Archive to hold fully the original documents – yet with restricted access – and in addition a similar service like the NPÖ will be established.

Since the access to NPÖ is currently foreseen for health professionals only, questions on how patients should be able to access their full data are not relevant at this point.

4.2 Centralised and/or federated architecture for EHR

For Sweden the benefit of the chosen solution is the efficiency of the over-all system. A central index as sole technology would imply to access the data steadily in the primary – often legacy – systems.

As a result of questions raised, the NPÖ architecture is characterised as a federated system, i.e. the primary data will remain in the systems of the care providers while the focus of the

project is to establish the query and reply service. The technology used for the federation is the product 'Ensemble' by InterSystems.

4.3 Content and Coding of the National Patient Summary/Overview

It has been noted that the Swedish Patient Overview resembles a quite comprehensive electronic health record as compared to the "minimal data sets" used by many countries (examples e.g. from Germany and Italy).

Finland stresses the importance of using standardised structures of codes, classifications and terminology as well as standards like CDA[1].

As already mentioned when discussing the full infrastructure, physician cannot communicate medical information by using codes alone. Using the "Applied Information System" (AIS) approach – presented as an interim solution the National Information (NI) structure project – the documentation in the NPÖ comprises structured data (e.g. for lab results) and free text information. Yet all information is structured by keywords.

Opposed to that some of the national registers (like e.g. for chronic heart failure) are successfully working with 100 % formalised information. The operational environment of these registers is however not subject to the "4 minutes" constraints a clinician has to enter data in an EHR[2].

Still the role of adequate rules and good support for the clinicians as primary source of clinical data cannot be underestimated since the demands of health systems for structured and coded information can only be supported on the ground of suitable documentation in the clinical EHR.

Also from an international perspective, it is evident that the epSOS minimal data set will be easily covered by the data present in the NPÖ already. Yet translation will be a critical issue.

4.4 Deployment, testing and risk assessment

For the time being the project has been successfully launched in one county and the ambitious goal is to extend the project to all 21 counties by 2011. Achievement of this aim might be supported by the financing mechanism, since all counties pay based on the number of inhabitants, regardless whether they implement the solution or not.

Based on some experience from projects in England, there might be more time needed to implement the solution. Time consuming elements would be compliance testing and clinical risk assessment. For the latter it has to be taken into account that making available of data is also linked to new risks, i.e. information newly available could lead to the wrong conclusions.

Sweden will accompany the implementation by an evaluation through the local university.

[1] Post script from Päivi Hämäläinen: "It could be more strongly emphasised that the commonly agreed descriptions of them all [i.e. coding, classifications and terminology] are very important. Sharing structured data does not help if the understanding on the meaning of the data differs. This is an important issue in both national and international data sharing. It is also important to note that the same understanding of definitions does not come by itself, but needs working together."

[2] This constraint has been highlighted by Nils Schönström in his presentation on "The Swedish Architectural approach - Semantic aspects".

5 Web Services / Public e-Services

The new services have been introduced by Lars-Erik Öjerås, Swedish Healthcare Direct.

Starting from the existing www.sjukvårdsrådgivningen.se, i.e. a web portal providing high quality health information, new services for Health Care on the Internet (Vården på webben) are implemented. Interactive services will comprise guidance on best care, appointment scheduling and repeat prescriptions; the portal will be complemented by a phone service.

5.1 Trustworthy Health Information on the web: Review and Quality Assurance

The meeting has acknowledged that health information provided by a public portal should be trustworthy for consumers and patients. The application of international criteria like the HON code may support this. Referring to information quality, Sweden reports that, 50 employees within Sjukvardradgivningen (SVR) take care for providing accurate health information and – in addition – the National Board of Healthcare supervises the quality of information and has done studies applying international guidelines.

5.2 From pure information to e-services: Will healthcare become a self-service?

New services may even lead to a competing usage of personal health data by patients and by physicians. Likewise, in Germany, the Social Code V foresees competing regulations on EHR access, i.e. a personal health record managed by the patients and the traditional medical record managed by physicians.

In Denmark, some patients may already by today (within a pilot project) access their lifelong health data via www.sundhed.dk. That access is fully and directly without any filtering. The population is very interested in this service. At the same time, there is a discussion on the further development of sundhed.dk towards a universal service portal for healthcare.

In England, a significant move from information providing portals to shared patient records is observed. To help setting up such services, patient organisations have been involved for collaboration; also services like home care are being integrated into the patient record documentation.

For Sweden the process of defining what information would be directly accessed by patients is still ongoing; yet those decisions have to be taken by the architectural board at SALAR.

5.3 Data owner or data custodian?

Since the provision of e-services involves personal health data, it definitely needs mechanisms for authentication/authorisation and security; also the challenges on the issues of data ownership have to be solved.

For this, Europe today offers a broad spectrum of regulations: While some nations stress the data ownership of the patient, others prefer to apply the concept of healthcare provider organisations being the “custodian” of patient data.

It was noted indeed that from a legal perspective, one can hardly “own” data since “data” is a volatile concept, i.e. when someone “gives” data, he can continue to use it in the same time

and when someone "lent" data he/she cannot get it back. That's why the concept of "mastering" data usage is often seen as more appropriate[3].

Unanimously it is understood that – for liability reasons – patient data can never be completely deleted.

6 Decision support for prescribing of drugs

The tools for decision support for prescribing were introduced by Marie Eliasson, Project Manager. The subject is closely related to the presentation of Bengt Åstrand, Apoteket AB.

The Swedish Drug Information Database (SIL) holds comprehensive information in order to make decisions based on quality-assured drug information and to support prescribers at each stage of the decision-making process. PASCAL extends this system by providing individualised information, i.e. a record on all medications dispensed for a particular patient. All this information is to be displayed at the point of care in support of health professionals.

6.1 Over-alerting for medication risks and drug interactions

There is already quite some international evidence on alerting systems for drug interactions. E.g. while the German Health Card project has postponed the ePrescribing application for now, still nearly all office based physicians have already access to databases providing information on medication risks and drug interactions. At the same time, 100 % of the pharmacies are using such systems in Germany.

Still medication safety needs improvement and there are particularly well-known problems of over-alerting and the missing integration of the Electronic Health Records systems with the decision support systems for ePrescribing. It was proposed to further consider cross-border collaboration on this issue.

England supports this view on over-alerts. The problems exist particularly in secondary care while the adoption of the drug information and decision support for prescribing in primary care is easier..

6.2 Medication identification / Drug naming

Another aspect of patient safety in all (e)prescribing settings is the correct medication identification, closely related to drug naming and coding. While Sweden and many other nations use brand names for naming, England uses generic names to ease replacement.

Drug coding is far from being unified in Europe. Germany uses PZN (central pharmaceutical code, given as number and barcode), Sweden applies the identifiers NPL-ID and NPL-Pack-ID – also to products from outside of Sweden.

While this is typical of "old" European nations, many Eastern European Countries have moved to the GS1-GTIN 13 digit code.

[3] Note from the authors of the report: The EHTEL "Patient Charter for eHealth Information Systems", issued by the EHTEL Working Group "Patients and Citizens" in 2003 and refreshed in 2008 does not say anything different.

Here – cf. also epSOS – every European move towards unified systems should be observed. Hereto, this question may be a subject for further cross-border collaboration.

7 E-Prescribing and drug lists

The subject was introduced by Bengt Åstrand, Apoteket AB.

While first electronic prescriptions started in the 1980ies, the newly established 3 medication databases mark a new phase of ePrescribing with full transparency and decision support:

- ⇨ National Pharmacy Register stores for 15 months all dispensed medications; does not need the consent of the person/patient; does not mention the prescribing physician.
- ⇨ Prescribed drug register = National Database for Ordination (NOD), holds all information related to a patient's drug therapy. Also allows patients access to their drug therapies.
- ⇨ Online Prescription Repository. Drugs can be "ordered" from the pharmacy by providing the name and a transaction code. Starting in June 2006 now (Jan 2009) 5.000.000 prescriptions are stored monthly in the database.

7.1 Added value and usage of the medication data bases

That system is impressively complete compared to other implementations in Europe. Yet it was suggested to add the OTC, i.e. prescription-free, drugs to safeguard full patient safety. An explanation is needed for the small figures reported on the usage so far. It should be analysed whether physicians do not accept the system or have already all necessary information on medication in their local system, thus not needing the central databases.

Sweden explains that the liberalisation of the pharmaceutical market in Sweden will make it more difficult to include the OTC medication into the databases, since those may be sold at groceries in the future, since The current monopoly of Apoteket will be discontinued by the middle of 2009.

Some regulations in Denmark have resulted in strong financial driving factors for the usage of medication information services by the citizens/patients:
1) Patients have to pay all medication themselves up to a limit of DK 3000, and then 50 % up to DK 6000, only beyond this there is no co-payment. Hence patients need to access the database to learn their current co-payment status. 2) Physicians are reimbursed on a per prescription basis. 3) Pharmacists are obliged to check generic replacement drugs for the prescriptions.

Yet the Swedish approach is focused on patient safety and that element is still extended: The databases are also used to improve pharmacotherapy and dispensation of drugs to elderly people. For the elderly in particular, often various sources of prescriptions exist and the databases help to identify and to avoid overmedications.

7.2 Privacy issues for medication records; are there differences to other EHR information?

The full recording and availability of all dispensed medication stimulated again a short debate on data ownership and privacy rights (cf. section 5.3 above); e.g. in Germany a patient is planned to be entitled to selectively hide prescriptions from certain pharmacists, i.e. to buy

"normal" medication at the well-known pharmacy and "sensitive" medication (Viagra ..) at an internet pharmacy.

It was also considered that patient representatives would insist that patients have rights not to disclose some of their information to the respective health professionals.

Nevertheless, it was noted that the privacy issue can be handled with much less flexibility in an ePrescribing context than in an EHR one.

In fact, besides the patient safety aspects, the administrative use of the medication data limits the privacy which can be granted for medication related data.

On the other hand, it is also reminded that political debates on privacy may be biased by fears of to much public control on the physicians prescribing decisions.

For the privacy of patients, Sweden confirms that there is no opt-out foreseen from the National Pharmacy Register. For prescribing patterns: The prescribing physician is not mentioned here, still researchers can order files for analysis of prescribing patterns.

8 Summary of experiences and lessons learnt from the workshop

For ease of reading, the rapporteurs have not documented the final round as separate text. Yet the discussions held for each element and the lessons learned added in the final round have been merged in the text above (sections 1 – 7). That means each section provides all comments of the European experts and respective explanations/assessments from Sweden.

As additional input, Alexander Schanner from ARGE ELGA in Austria provides a comparison of the key elements of the national projects plans in Austria with the Swedish approach (cf. PPT presentation available from the file repository): Overall, a similar task definition like in Sweden is also observed in Austria. It is particular emphasis given to the fact, that – from the viewpoint of European collaboration – it is most important to have a compatible approach to the distribution of data between decentral (federated) and central systems since only the central systems will communicate on the European level.

Gösta Malmer and Mats Larson thank all participants for their active contribution.

It was concluded that a similar workshop would be useful in approx. 18 month, both to assess the implementation status of the demonstrated projects plans, to reflect on the next steps and to strengthen communication and collaboration for European national eHealth strategies and projects.

9 Annex – List of participants

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