



Health ID Management in Europe 2006

- one touchstone for interoperability -

Summary & Conclusions

Health ID Management Workshop

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Ministry of Health, Welfare and Sport







Health ID Management in Europe

20th and 21th March 2006, Schiphol Amsterdam

On behalf of EHTEL, the Dutch Ministry of Health, Welfare and Sport and NICTIZ and in the framework of the i2-Health project (funded by eTEN/European Commission) an expert conference was held at Schiphol on Health ID Management in Europe and interoperability.

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I. Opening



Hans Haveman

(Senior Policy Advisor, Pg. Unit Health ICT, Dutch Ministry of Health, Welfare and Sport)

82 people from 21 countries

On the afternoon of Monday 20th March, all participants of the international expert conference on Health ID Management were welcomed by Hans Haveman, policy advisor within the unit Health ICT of the Dutch Ministry of Health, Welfare and Sport (VWS). '82 people from 21 countries including Japan have come to Schiphol for this expert conference which was organized by Ehtel, i2-Health, NICTIZ, VWS and CIBG,' he said in his opening speech. Hans Haveman emphasized the importance of checking interoperability with other countries and pointed out that identity

management is one of the three priority topics of the e-health working group of the European Union. 'There is a lot of work ahead. Besides good organization and delicious food, you need an excellent chairman.' With these words he ended his speech and introduced the chairman of the conference, Niels Rossing.

2. Welcome & Introduction

Niels Rossing (Chairman Expert Conference)

'A touchstone for interoperability'

Niels Rossing of the Danish Health Care Network, chairman of the Health ID congress, started his introduction by saying that he has been working in this field for more than twenty years, and that much progress has been made. 'Recently, for instance, not only the EU presses for transnational interoperability. Also a WHO Member State resolution has been adopted urging the 192 member states to make strategies for ICT and healthcare.

The European Union realizes, now that persons are moving freely across borders, they have to cope with the problem of interoperability. We all know how hard it is to realize this on a national scale, so it's even more difficult across national borders in Europe. But it is necessary.'

Together with the drive for "the patient summary" and the "emergency data set" the ID management and therefore the Health ID congress is a touchstone for interoperability, according to Mr. Rossing. There are a lot of aspects involved. Interoperability is not only a question of agreeing on standards. Of course that is very important, but there is more to it. There's also the need for semantic, linguistic, legal and political interoperability, and for cultural acceptance. And the goal of it all: when we're on the Greek islands for a holiday, insurers and healthcare professionals will treat you like home. 'But also the free movement of services across borders necessitates identification management. This is because if you as a patient use foreign health care service from home you must be sure that you are talking to the right and a qualified person. How do you know that it is not a dog at the other end of the internet. Thus important issues are identification, authentication and autho-



Niels Rossing, the chairman of the conference

ization, of patients and of healthcare professionals said Mr. Rossing. How can we be sure that this person is the person he claims to be? That's the main issue at stake here. It's very important for all stakeholders to now that Mrs. Smith is Mrs. Smith, that her doctor is her doctor, and that her insurer is her insurer. We are looking forward to hear what our solutions should be.'



3. Dutch Expectations for Health ID Management



Ellen Maat (Head of Programme Unit Health IT, Dutch Ministry of Health, Welfare and Sport)

'ID management is the foundation for a reliable system'

'In the Netherlands we have been working on ID management for several years now,' said Ellen Maat, head of the unit Health ICT at the Dutch Ministry of Health, Welfare and Sport. 'The main objective of the Dutch health ICT program is to improve the quality and efficiency of healthcare, by creating the preconditions for an optimum and safe usage of ICT; and ID management is the foundation for a reliable system,' she continued. The Dutch identifying system aims at the entire healthcare sector: the citizen service number for the identification of citizens/patients, the unique healthcare professional identification and the unique health insurer identification. The citizen service number will be issued in 2006 and is identical to the current social security number. This number does not provide any information and vest any right. For several reasons there will be no separate number for healthcare: one number is easier; this number is already printed in passports and it has been endorsed by the Data Protection Authority. Introduction of the citizen service number in the healthcare sector requires new legislation to ensure that all parties use the number and to regulate the protection of personal data and the obligation for identification.

How will it work in practice? The first step is the identification of the patient. After that, verification of the citizen service number has to be effected through the SBV-Z, the register that checks the number and gives minimal data about the patient, where he lives for example.

For the unique healthcare professional identification, registered healthcare professionals receive what is known as a UZI card. This card has three functions: authentication (are you who you say you are), confidentiality (guarantee for the sender that only the right recipient will receive the data) and irrefutability (electronic signature).

Finally, the Netherlands will also introduce a register for unique insurer identification. Insurers don't have access to medical data, but will use ICT facilities for communications about payments. At the moment experts are working on authentication certificates for insurers, on the same lines as the UZI cards.



Ellen Maat

4. EU Policies and Projects in search and support of interoperability

Octavian Purcarea (CEC, DG INFSO)

Working towards a recommendation

'eHealth Interoperability Activities in the area of Patient Identity' – that was the title of a presentation by Octavian Purcarea, DG INFSO of the EU Commission. The European eHealth Action Plan, Mr. Purcarea explained, consists of – among other things – national and regional roadmaps, interoperability standards for electronic health records and messaging, and a legal framework. The purpose is to reach agreement with all stakeholders on a 'European Recommendation on eHealth Interoperability'. The ultimate goal is of course 'to enable access to the patient's electronic health record, patient summary and emergency data from any place in Europe.' Mr. Purcarea gave four answers to his own rhetorical question 'Why all these efforts?':

- Lack of interoperability is detrimental to patients (because of the lack of information, medical errors and limited mobility), to healthcare professionals (because of difficult access to health records), to health managers (because of the lack of a basis for economic analysis), to researchers (because of reduced availability of medical data) and to the industry (because of a reduced market share).
- Research & Development in eHealth has resulted in clear evidence of eHealth benefits, including financial benefits.
- Local and regional pilots need to scale up to support national and EU-wide services.
- The eHealth Action plan calls for joint EU and member states' action to find the best approaches and guidelines on interoperability of eHealth systems by the end of 2006.

Specific topics identified as a priority by the eHealth Working Group can be topics such as a patient summary, patient and practitioner identifiers and an emergency data set, including confidentiality and privacy issues, as well as contact with implementation authorities. The topics can be explored by mixed ad-hoc subgroups with the support of the standards development organisations. Participation in such working groups could be optional, according to Mr. Purcarea.

The results of a patient identity study were a proposal for a strategy to achieve the interoperability between existing e-health and health systems rather than creating a complete new system, a proposal on how to approach the issue of patient identifiers at European level, and a modelling of the patient identification process in different countries and at EU-level using the so-called Unified Modelling Language (UML).

Mr. Purcarea ended his speech by saying that a Commission staff



Octavian Purcarea

working paper on interoperability will be published in the near future. Further consultation of stakeholders will take place in the beginning of 2007, in order to allow the refinement of the Recommendation on eHealth Interoperability. After 2007 further topics will be developed, such as e-prescribing; harmonization of the legal framework will take place, together with monitoring the implementation of the Recommendation on eHealth Interoperability.

5. Framework for European and Global eHealth interoperability



Karl Stroetmann (i2-Health, empirica)

'Interoperability is a long term process'

'The i2-Health project was developed when hardly anyone was talking about interoperability,' says Karl Stroetmann, member of the i2-Health team. The aim of the project was to establish a framework for European and global e-health interoperability.

At the moment, many countries around the world, including Australia, Canada, Czech Republic, Denmark, France, Germany, the United Kingdom and the USA, are trying to improve interoperability. Key aspects are that health is the most information intensive sector of our economies, collaboration within and across jurisdictions is driving information exchange, and by recording the information once you can use it many times.

'An integrated system is needed to improve the safety and effectiveness of healthcare,' Stroetmann continues. 'We do not only need interoperability among systems. Ultimately, the doctor has to provide optimum service to the patient in a variety of surroundings. The doctor is not a machine. Much more than technical interoperability we need semantic and cultural interoperability. And professional organisational collaboration is also needed, as is policy level cooperation within and across jurisdictions.'

In his concluding remarks Stroetmann pointed out that we have to be aware of the fact that health systems are large, complex and dynamic, and that interoperability is a long term process. 'Adequate structures and processes must be established at regional, national, European and global level. Politicians have to create the framework, researchers should carry out analyses, and professionals in health have to take care of the implementation. The involvement of the industry is indispensable. It is important that member states and organisations like NICTIZ organise workshops to prepare and facilitate the industry. Harvesting the potential benefits for all requires a dynamic process approach beyond standardisation activities.'

The i2-Health project started in February 2005 and will end in February 2007. The consortium consists of the Empirica institute for

Communication and Technology Research in Bonn, the European Health Telematics Association (Ehtel) in Brussels and a steering committee of member state health authorities. The project is being supported by the eTEN Program of the European Commission.

www.i2-health.org



Karl Stroetmann



6. Health ID Management: Concepts and models for interoperability



Ramin Tavakolian (i2-Health, WP-Lead ID Management)

'Bullet proof instead of a firm handshake'

'Currently identification and authentication of actors in domestic healthcare is a mixture of administrative measures, common sense and personal human interaction,' said Ramin Tavakolian of the Central Institute of Ambulatory Health Care in Germany. 'To fake a physician in conventional setting you need an office, yellow pages listing, a big desk, nice manners, framed diploma's, and a firm handshake. To fake a physician in the electronic world you just need a digital certificate file.'

Therefore, these certificates need to be trustworthy and thoroughly designed, even 'bullet proof', stipulated Mr. Tavakolian. A Trusted Third Party (TTP) is therefore needed, so that any user of the electronic health record can be sure that the system is safe. Besides, a layer model of ID management can be defined, consisting of political and legal, organisational, semantic and technical issues. The technical layer deals with certificates, ID tokens and network

infrastructure. The semantic layer deals with data models and identifiers, on which Mr. Tavakolian remarked that biometric identification can be dangerous, because if the data are copied, there's no way back, Partly better is to use permanent identifiers such as social security numbers, of which alteration is organisationally difficult. Once privacy aspects have been comprehensively analysed, modern implementations will bias towards temporary identifiers. In all cases any semantic load on identifiers will cause privacy difficulties.

The organisational layer of ID management deals with questions like: what elements are to be identified (healthcare professionals, patients and so on), how is the registration process organised and who is authorised to register entities? 'All these layers have to be perfectly arranged, otherwise problems will occur. Here the interoperability is at stake'

Because of the immense amount of details involved on each layer, it is not realistic to aim for ubiquitous interoperability of IDM. There will be simply no resources for that. The right approach is to focus on concrete specific cross border use cases that are either regulated on European level or meet demands from patients or health care professionals, according to Mr. Tavakolian:

- Define priority use cases (mobile patient, mobile healthcare professional, cross border health message)
- Analyse existing base matched with interoperability layer model
- Perform a gap analysis
- Facilitate solution.

One of the examples given was the case of a cross border health message. The medical data of the patient must be transmitted by a physician in country A to a colleague in country B. First the e-mail address of the recipient must be located, then the identity and professional attribute of the recipient must be confirmed, afterwards the message must be securely transmitted and at last the receiving physician must receive confirmation of the ID and professional attribute of the sender.



Ramin Tavakolian



7. Expert Parallel Sessions on Health ID Management



Session 1: Health Professionals & Health Care Organisations

Track 1 Policy & Legal Issues

Chair: Roy Tomeij

Introduction: Lilian Theunissen

Rapporteur: Ramin Tavakolian

Summary

'The patient will be in the lead'

'European cross-border access procedures to electronic health records will require the highest level of individual personal identification,' says reporter Ramin Tavakolian. 'Other access identification options such as institutional identities are not recommended for cross-border scenarios. This does not exclude individual bilateral arrangement between member states, if both have a softer mechanism of identification in place.

'The linkage of a health professional attribute or qualification is also required. The recognition of such additional information calls for a legal procedure, for example by international contractual agreements between responsible authorities to enable policy bridging. To support the conclusion of policy bridging agreements, responsible authorities should receive relevant and reliable information of other member states: for issuing of e-health identification, health-care professional registers and health professional cards, as applicable. 'In all access scenarios to electronic health records, the patient will be in the lead as far as reading files and granting access to his file. The existing or planned scenarios for enabling the patient to exercise such access control differ, and are still immature in a number of member states. Additional rights to delete or ask for deletion are controversial since they conflict with doctors' obligation to document data. Finally, log files for access procedures to electronic health records are required to record the identification data of accessing individuals.'

Discussion

'Why should I believe you?'

'One of the most important questions in electronic communication is: why should I believe that you are who you say you are?' That was the first sentence of Lilian Theunissen of the UZI-register, a facility set up to uniquely identify healthcare professionals in the Netherlands, in her introduction to the parallel sessions for 'Health professionals and healthcare organisations'. The goal of these sessions, according to Mrs. Theunissen, was to create an overview of the choices of the European member states regarding ID management of healthcare professionals, and to identify the implications of these choices when put into a European perspective. For that purpose, a questionnaire had been sent to all participants



Lilian Theunissen

in the conference, and the results made clear how big the differences in Europe still are. For example: Belgium proved to be one of the few countries with a Public Key Infrastructure based on a national e-ID card. France and the Netherlands are examples of countries that include assistants to a healthcare professional in the PKI domain, and Austria was believed to be a country with no requirement for a secure electronic signature. 'I would like to make some remarks on this issue, but I must first warn you that the questionnaires have not been validated,' Mrs. Theunissen warned. In the field of European health ID there are at least four technical standards involved, which of course makes communication no easier, as Mrs Theunissen pointed out. The percentage of health-care professionals having an electronic ID varies widely, from 1% in the Netherlands to 100% in Belgium. Again: this is according to the participants who filled in the questionnaire.

The need to verify

The main questions of track 1 of the parallel sessions, on Policy & Legal Issues, dealt entirely with trust. 'To make cross-border access to electronic health records possible, we need to verify certain

things,' Lilian Theunissen said in her introduction to this parallel session. 'The system needs to know who you are, what you are and what you are allowed to do or see. It is also necessary that a record can be kept of what you have done.'

On the first question – who are you? – Piet Burger of the Dutch Order of Medical Specialists remarked that it is important to know whether you push or pull information. In other words: do you put information on to the server, or are you asking for information? This question raised some discussion, but in the end Gerard Freriks of CEN stated: 'It doesn't really make any difference, trust is always needed,' and everyone agreed.

Irma Turenhout of the Dutch UZI-register, added that there are four levels of trust, and the Dutch ID known as a 'UZI-card' is a device at the highest level. Representatives of other countries remarked that such levels of trust have not yet been reached in their countries. In Hungary, for example, a legal electronic signature does not exist yet, although there are some pilot projects in the north of the country. 'To create a trustworthy system, an electronic signature is not really necessary,' was the opinion of Lilian Theunissen on this issue.

The goals to be reached for trustworthy systems are nevertheless very high, as everyone at the parallel session agreed. On certain issues, like being contaminated with the HIV-virus, a percentage of 99 is not enough. You need to be one hundred percent sure that the information is correct and safe. 'Although this of course depends on the costs,' remarked the representative of Hungary. 'And the amount of trouble for the doctor involved,' Piet Burger added. To which Gerard Freriks added: 'The only thing that really matters is that you can prove your identity.'

A new question popped up: How can we maintain cross-border trust? 'Can we trust with low trust levels, as we heard earlier?', Roy Tomeij, chairman of the parallel session, wanted to know.

'That's what we're here for, to get information about each other,' Lilian Theunissen remarked.

'The EU has a duty here,' said Piet Burger. 'Trust alone is not sufficient, you have to build a legal system, and at least you need to have a code of conduct. Of course, trust is very important as well.' 'But how can we trust each other in Europe?', Mr. Tomeij continued. 'Do we, for example, need to be able to trust the registers of healthcare professionals of all countries? "Of course,' said Mr. Mennerat of the French Ministry of Health. 'If you accept driving licenses from other countries, you have to accept their registers that state that a certain person is a doctor as well.'

'I agree, but the problem is: I don't know which organisations are issuing certificates in each country,' Lilian Theunissen said. 'When issues of authorization are at stake, I'd like to know: am I communicating with the right parties? Again, I think, a good reason to meet each other at conferences like this.'

The key role of the patient

The next morning the parallel session on Policy & Legal Issues continued, quite early, according to some participants, at 8.30. Nevertheless there was a lot of lively discussion this morning on the questions: 'what are you?', 'what are you allowed?' and 'what have you done?'

Another important issue proved to be the 'key role of the patient,'

as Roy Tomeij put it. 'The patient is the sole owner of the information in his record,' Jan van der Loos of software producer HISLink remarked. 'No, that's too strong,' replied Theo Hooghiemstra, former legal affairs manager at NICTIZ, the Dutch National IT Institute for Healthcare. 'The role of the patient has been made clear in Dutch legislation, and he has many rights, but he's not the sole owner.' But Mr. Van der Loos was not convinced. 'As a patient, I am the owner of my data,' he insisted. 'At this moment, the patient in Denmark is already in the lead, following directives of the EU concerning the protection of data,' said chairman of the conference Niels Rossing, who was a guest this morning. 'When information is transferred from one hospital to another, the consent of the patient is needed. For obvious reasons, this consent is not needed in the case of an emergency. But, in the end, the electronic data are owned by the patient.'

'According to French law, patients also own their medical data. But the question is: what are those data exactly? Do they include the private notes of the doctor? There's an ongoing debate on this issue in my country,' Mr. Mennerat said.

Does the patient have the right to eradicate parts of his record?, Mr. Tomeij wanted to know.

'He is not allowed to change it directly,' Mr. Rossing answered. The healthcare providers in the room agreed on this point, because, they said, it is impossible for a doctor to defend himself when something goes wrong, and the patient has deleted information. 'An electronic health record that has been changed by a patient is therefore not a legal document anymore,' Theo Hooghiemstra said. Of course, others remarked, patients are allowed to ask their healthcare professionals to delete information. 'But when all the files are handed over to the patient, the healthcare professional can no longer be held accountable,' Piet Burger repeated.

A real electronic record?

The electronic health record is a big issue all over Europe – that was made clear by all the participants at the parallel session on Policy & Legal Issues, but a real electronic record isn't functioning



anywhere yet. 'In France, every patient should have his own electronic health record by July 2007, but the project hasn't started yet. There will be general elections next year, you know,' Mr. Mennerat explained.

'In Germany there's a discussion about the storage of the information: should it be put on a smartcard or on a server?', said Ramin Tavakolian of the Central Institute of Ambulatory Health Care. 'To be honest, this discussion has come to an impasse. We are bogged down in efforts to the hardware working. In Denmark the system is quicker and more flexible. But in Germany, privacy is a big issue, as it is in the Netherlands, and that takes a lot of time.'

'In Greece, we do not have an existing electronic health record either,' Mrs. Zoi Kolitsi of the Greek Ministry of Health added. 'This is also because of rigorous legislation on confidentiality.'

Of course, Roy Tomeij concluded, all these problems have to do with logging, in other words with the question: what have you done? 'What's the situation on this issue in the different countries present at this table?', he wanted to know.

'In Denmark we have a general logging on all cases of e-government,' Niels Rossing said. 'This includes e-health, and also taxes for instance.'

'In Holland, a "National Switchboard" has been created for the electronic communication of medical data,' Daryll Berend of software producer CSC added. 'All national communication is therefore logged. But of course this isn't the case in all hospitals.'

'It should always be logged, though,' added Mr. Freriks of CEN.

'Why? Doctors are so busy, they don't have time to look in other doctors' patient records,' Piet Burger replied.

'That may be true, but you do need a rule,' remarked Mr. Rossing. 'On the other hand, you have to be pragmatic as well. For instance: when a patient is handed over to another healthcare professional, because someone's shift is over; it isn't always easy or even in the interest of the patient to log out and log in again. In that case it's better that the new doctor continues with his colleague's record. In Denmark, we have decided to do it this way. And if somebody nevertheless wants to start a law suit, we'll just have to wait and see.'

'How is the logging supervised?', Piet Burger enquired. 'Make this logging available to the patient, that's the most effective thing you can do,' Gerard Freriks remarked.

'Does the patient have to have a key role in this part as well?', Mr. Tomeij asked. 'Because he's the first one to suspect abuse?'

'If I were a patient, I wouldn't check my health record daily,' Piet Burger said.

'And what about paper records?', asked Mr. Tomeij.

'Paper records are safe, because you never can find them,' Gerard Freriks joked.

'All right, let's end the discussion here,' Mr. Tomeij concluded, looking at his watch. 'I'll write the conclusions on the board.'

He turned around, and wrote the following recommendations on the whiteboard:

1. The electronic communication of medical data calls for the highest level of security.
2. As a healthcare professional, you have to prove who you are and what you are e.g. Mrs. J.A. Claassen, general practitioner
3. There is a need to identify who is responsible for ID in each country.
4. The patient should be in the lead in reading and having access to his record.
5. There should always be logging.
6. There should be an adequate system of supervising the logging process.

Everyone agreed on these conclusions, and then it was time for a coffee break and the next lecture, on health cards.



Stephan Schug

8. Expert Parallel Sessions on Health ID Management



Session 1: Health Professionals & Health Care Organisations

Track 2 Architecture & Implementation

Chair: Mark Bressers

Introduction: Jacob Moehn

Rapporteur: Stephan Schug

Summary

'We have to acknowledge the legitimate existence of some already established – and in fact different - National approaches for digital identifiers in Europe'

'The ultimate goal is to enable access to the patient's electronic health record, patient summary and emergency data from any place in Europe,' says reporter Stephan Schug. 'What makes it difficult is that member states take the freedom to organize the access to the patient's electronic health record in their own way. Different assumptions, different organisational needs, different business cases and different histories are some of the showstoppers.

'Identifiers and numbering systems were the architectural aspects we discussed in this session. With respect to the technical issue, we spoke about certificates. Also we talked about authorisation because identification and certificates are important means for authorisation.'

'For cross border access to electronic health records several aspects have to be established: who are you, what are you, what are you allowed, what are you doing and what have you done.

And there needs to be supervision over this whole process. With respect to the first aspect, who are you, the requirements for identifiers are easy to establish. Identifiers should be globally unique and meaningless and should have a long term persistency and a

defined format. There are three national approaches for identifiers in Europe: complete subject distinguished name of certificate, object identifiers with root and extension, and ISO country code and local ID which is globally unique. An additional European ID is not under consideration, because it is not feasible from a political point of view. Also there can be made a choice between a separate ID for the health system or reuse of the ID used for ID-card and passport. Because different approaches will persist, methods for mutual usage will have to be established. It should be investigated if a master professional index or something similar is needed.'

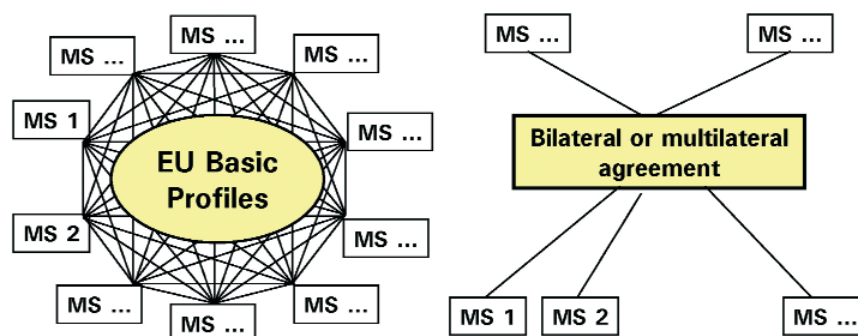
'There are also different technical approaches for establishing what you are. In France and The Netherlands they chose for public key certificates, in Germany for attribute certificates and in Belgium for a directory.

'Trust will be needed across jurisdictions. The existing framework for trust exists of the EU Directive for electronic Signatures, standards and guidance of ETSI TS 101 456 and the fact that qualified signatures are legally binding within the EU.

'The best approach is a flexible approach with the possibility of making bilateral or multilateral agreements as well as working on EU basic profiles.

'Finally some general recommendations are to agree on essential use cases, to identify open issues specific for health care and to have an inventory of existing solutions and regulations.'

Trust across jurisdictions is needed



A flexible approach would allow for setting up bilateral or multilateral agreements as well as using EU basic profiles

"From the rapporteurs presentation, drawing by Jacob Moehn"



9. Expert Parallel Sessions on Health ID Management



Session 2: Citizens, Insured Persons and Patients

Chair: Karl Stroetmann

Introduction: Peter Lau

Rapporteur: Marc Lange

Summary

'Identity management for patient, citizen and insured person'

'In the session about identity management (IDM) for patient, citizen and insured person we have spoken about privacy, vehicle and infrastructure for IDM and authorisation management,' says reporter Marc Lange. 'Here I will present the lessons learned with respect to these subjects and the implications of the lessons learned for the implementation approach and interoperability issues.'

'When it comes to privacy and identity management domains, perception is as important as reality. The presentations in this session by experts from different countries make it clear that there is several possible choices with regard to identity management. Three country profiles can be distinguished: one IDM system across all sectors, a common IDM for several domains with sectoral IDs and one IDM dedicated to the health sector. Furthermore contextual related IDM systems can coexist. For example, inside an organisation, for exchanging data and for building a general electronic health record (EHR) or an EHR dedicated to a certain disease.

'With respect to vehicles and infrastructure we stated that an on-line system will offer more flexibility than an off-line system and more and more a card is considered to be used as a key for on-line access to data. An independent portal or switching point will be needed for identification and authentication, as for federating different databases. IDM implementation can be implemented quickly, but there is a long migration phase for the deployment of the IDM infrastructure on health professionals' premises. Therefore there is a need for parallel and concurrent use of off-line and on-line systems. 'Finally we came to the matter of authorization management, which

in the eHealth environment is also called "patient consent". Within the framework of authorization management, confidentiality requirements depend on the application concerned. Three models can be distinguished for implementing patient consent: ex post control by log files and legal measures or ex ante control with the choice between an 'opt out' or 'opt in' strategy. For implementing the ex ante model, there is a need for a consent management database. This model offers a choice of granularity: role models per categories of health professionals or content models per categories of data. These three models for patient consent can also be used complementarily. With regard to field implementation the market and organization readiness should be taken in to account, as should the concerns about the human and technical feasibility of authorisation solutions. It is important to learn by doing. The best thing to do is to start with an approach that is feasible.

'One of the areas for further cooperation is the consent management implementation approach. Market readiness can be speeded up by launching a pilot and discussing the possibilities with the ICT industry. The electronic European Health Identity Card model (eEHIC) can also be further explored for replication in the eHealth domain. However, it is first of all it is important to agree on the aims of this interoperability. Do we want interoperability for sending a bill abroad or do we also want to be able to retrieve a health file from abroad? Furthermore it is important to take into account that re-using the eEHIC model for eHealth implementation doesn't mean that the same system is operational both in the field of social security and eHealth. Finally there should be further cooperation on registration authority recognition. We need to agree on common quality criteria, which are not the same as the requirements for face to face and remote situations.'



Marc Lange



10. EU Data Protection Act and Health Statistics: problems to solve?



Walter Deville NIVEL (NL Institute for Health Services Research)

'Sweden is a good example'

'As a scientist I am quite an outsider here,' said Walter Devillé of the Netherlands Institute for Health Services Research, 'but I am invited to make some comments on ID as well in European perspective, and I do so with great pleasure.'

One of the main issues of the EU Public Health Program 2003-2008, according to Mr. Devillé, is establishing and operating a sustainable health monitoring system, based on European-wide common agreed indicators. Goals are to provide regular reporting on health status in general, and to generate a flow of information, analysis and exchange of best practice in the public health field at European level. Some problems of healthcare professionals in this field, however, are related to data protection. 'There is confusion caused by European and national legislation, whereas national legislation is often more strict on privacy issues, and there is no guarantee of good quality or valid data. An ad hoc working group of Finland, Sweden, Malta, France, Spain and Estonia is trying to solve this.'

Problems confronted in the practice of – for example – the EU Network of Cancer Registries, according to Mr. Devillé, are not only

related to new member states, but also to countries like France, Germany and the Netherlands. These problems are among others the impossibility to use identifiable data and the interpretation of local data protection acts.

Different countries have a different approach to European directives, concluded Mr. Devillé, with an emphasis on data confidentiality procedures. 'Sweden offers a good example, with a right balance between mandatory participation and strong data protection. The ad hoc working group on this issue is meeting again in November in Utrecht, Holland, to work on practical solutions.'



Walter Deville



II. Identity Management: Existing Standards and New Work Items



Frans van Bommel (Chairman, ISO TC 215 WG5; Vektis)

Health cards and cross-border communication

'A lot of health cards solutions are isolated, not integrated in the surroundings,' said Frans van Bommel of VEKTIS, chairman of the ISO Working Group on Health Cards, in a lecture on 'Existing standards and new work items'. There are a lot of different views about health cards, Mr. van Bommel explained. For instance: a card can be an information container or give access to information, and it can be an application card or an identity card. There are also have been some lessons on this issue, for example: the best is the enemy of the better, 'because then nothing happens', it is better to start at a practical level and you must be sure that the relevant decision makers are aware of the need for standards.

When it comes to cross-border communication, different approaches are also possible. In the first approach, the patient and the card move across the border; there is an interoperability of technology and information, the identity is not healthcare specific and there is information access through portals. In the second approach the healthcare professional and the card stay in a country, there is interoperability of information, the identity is healthcare specific and there must be cross-border trust of institutes. Mr. Van Bommel mentioned some healthcare specific standards which are still being developed, such as the CEN TC251 standards and partly the CEN

TC224 standards which are now jointly being developed by ISO, CEN and ISO TC215.

In addition, Bernd Blobel, head of the eHealth Competence Center in Regensburg, Germany, mentioned some technical security services, such as access control management, audit control and data authentication, and made a distinction between cards with personal identification and cards with institutional identification. He also mentioned all the relevant ISO and CEN specifications, there turned out to be quite a large number according to chairman Niels Rossing. At the end of the lecture he asked: 'Are there any legal sanctions against countries that do not apply to these standards?' 'Unfortunately not,' Mr. Blobel replied.



Frans van Bommel



12. Privacy, Security and Trust with Federated Identity Management



Hellmuth Broda (Spokesperson Liberty Alliance)

'A global identifier won't be needed'

'Federal (pan-European) identity management will solve 80 to 90 percent of the problems we are discussing here,' says Hellmuth Broda, spokesperson of Liberty Alliance. Liberty Alliance is a network of over 150 diverse member companies and organizations from around the world which share knowledge and experiences about e-health. The network not only focuses on technology, but addresses the whole issue of identity including aspects such as policy, privacy, business, marketing, and interoperability conformance testing and certification.

'Liberty has privacy and security in mind from the first step,' says Broda. Therefore Liberty promotes a federated structure, which means that no single centralized data storage that would be vulnerable to attack. The end user has more control of the data because permissions travel with the data, guiding its use. According to Broda, no global identifier model would protect against unauthorized data sharing. He pointed out that a global identifier won't be needed. 'Vodafone doesn't know anything about me. When I use my mobile phone abroad, identification of my provider takes place: "Are you going to cover for this guy, are you going to pay our bills?"

They don't know my name, shoe size or anything else.'

Broda ended his presentation by calling on the public to join Liberty Alliance. 'Most of the members of Liberty Alliances are Americans. That's a pity, because it gives a local view of the world, by no means as diverse as it is in Europe.'

www.projectliberty.org



Hellmuth Broda



13. Joint Conclusions, Perspectives and Recommendations

Niels Rossing (Chairman Expert Conference)

'Keep it as simple as possible'

Chairman Niels Rossing ended the expert meeting on Health ID Management in Europe by thanking the organizers and giving some concluding remarks.

1. 'First of all, the discussions of today and yesterday made it clear that it is not the technology that excludes us from ICT, but it is the cultural framework within which we have developed our healthcare systems. The way you provide healthcare is the way you embed the ICT to make life easier for people. Although it is an ambitious goal to reach interoperability in Europe, it is still a very important one.'

2. 'Maybe it is a showstopper, but instead of reaching the exchange of full electronic health records from one country to another, partial elements may be relevant. There is no exclusive definition of an electronic health record, so you don't need to have full electronic health records on a nation-wide scale. The best may be the enemy of the better, so let's keep our feet on the ground.'

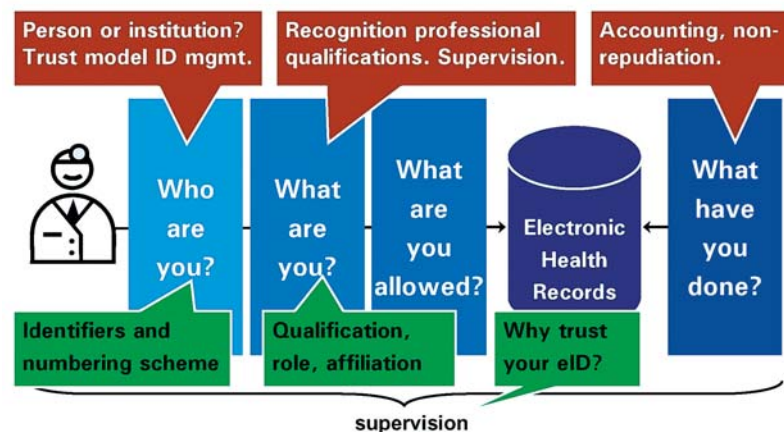
3. 'Work together and make your systems compatible with each other. Strive for simple systems, keep it as simple as possible.'

4. 'We already have the standards available and we should use them. You should not be naive thinking that everyone is going for the good. But if you always think of what could happen, there will be no progress. For example: your passport could be stolen or maybe you have a schizophrenic mother. It is a concern, but don't allow it to become a showstopper.'

5. 'In establishing what is relevant for identification, authentication and authorisation we need to take into account the perception of the citizen or patient. To make the electronic communication as secure as possible a good legal system is necessary. Identification is not so much of a problem. Authentication is much more complicated, because of the bipolarity, the issue of consent and the issue of trust in a doctor. We need a continuous down-to-earth registration of who is doing what in Europe. Basic and extended European agreements would be a real step forward.'

All the complete presentations that were held during this meeting can be found at www.nictiz.nl and www.ehtel.org.

HCP: Cross-Border Access to Patient Data



A clear conceptualisation is needed to make significant progress forward to allow for cross border access for patient data in the future. The first steps have been done and the tools are ready.

"Graph by Lilian Theunissen, CIBG"

Participant list



Belgium	Custodix NV Intel Corporation Europe, Middle East & Africa Mataranka Ministry of Health	The Netherlands	BT Global Services/GUIDE Cap Gemini Nederland Healthcare Cardlife BV Careliance CEN TC251 "European Standardization of Health Informatics" CIBG CSC Computer Sciences BV Epping Consultancy European Space Agency, ESTEC, HME Fujitsu Services HISLink BV ICTU KWIC Healthcare BV Ministry of Health, Welfare and Sport Ministry of the Interior National IT Institute for Healthcare in the Netherlands (NICTIZ) NIVEL Orde van Medisch Specialisten OWM Zorgverzekeraar Zorg en Zekerheid Porvoo Group eEurope Smart Cards Roy Tomeij BV Royal Dutch Society for Physical Therapy (KNGF) The Health Agency Vektis BV Vita Valley VU Medisch Centrum Zorgverzekeraars Nederland
Denmark	Danish Centre for Health Telematics Ramboll Management		ProRec Romania / UMF Timisoara Carelink Oracle Sweden NHIC Liberty Alliance Association for Quality in Healthcare
EHTEL	EHTEL		
EC	DG INFSO H I DG INFOS H DG EMPLOYMENT DG SANCO		
Finland	Helsinki University Central Hospital		
France	Eurorec GIE SESAM-VITALE GIP-CPS Carte de Professionel de Santé HC Forum Ministère de la Santé et de la Protection Sociale Oberthur Card Systems Ministry of Health		
Greece			
Germany	GSF- National Research Center Medis Institute Fraunhofer Institut Integrierte Schaltungen/eHealth Competence Center KV Bayerns Sagem Orga	Romania	
	National Institute for Strategic Health Research	Sweden	
Hungary		Slovakia	
i2-Health/eHealth ERA	empirica ZI	Switzerland	
Italy	Instituto di Fisiologia Clinica, CNR National Research Council	Turkey	
Japan	Tokyo Institute of Technology		
Latvia	Ministry of Health		
Luxembourg	Serice eLuxembourg		







For further information:

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