

CHANGING PERSPECTIVES ON INFORMATICS? *A Comparison of Three National Electronic Health Records*

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Abstract: Participatory approaches to health care are getting increasingly popular in Western countries. But are the perspectives on informatics changing as well? Because not every patient (always) can or wants to actively participate in his health care process, differentiation in medical encounters is needed. We use the term 'relational responsibility' to refer to a process in which doctor and patient are responsive to each other's norms, values and ideas, especially with respect to their role division. Health informatics can support or restrict this differentiation by giving patients access to Electronic Health Records (EHRs) and/or converging those records with Personal Health Records (consumer oriented informatics). When we look at the policies on the national EHRs in Canada, Denmark, and The Netherlands we find that the orientation towards informatics is still mainly provider-oriented. Even when policy makers emphasize the importance of patient participation and are aware of the potential of health informatics in this context, they have not given priority to translating this into the design of their EHR. This means that for the upcoming years EHRs will support one traditional role division: the one in which the health care professional is in the lead and is the better-informed party.

1 INTRODUCTION

There appears to be a worldwide trend towards the development of Electronic Health Records (EHRs). On all continents nationwide generic Electronic Health Records are being introduced (see e.g. EHTEL, 2008). In addition, there is a trend towards health records that are more directed towards use by patients – the so-called Personal Health Records (Tang et al., 2006).

Electronic Health Records are not 'just' a technical matter. On the contrary, they can be seen as the 'stabilization' (Chia, 1996) of norms, values and conceptions of 'good health care'. Ideas of a 'good' division of roles between doctor and patient are automated and thus stabilized in EHRs.

Analyzing the stabilization of such norms and values in EHRs is timely because of the increasing popularity of participatory approaches to health care

(Todres et al, 2007). An explanation for this popularity is that patient participation is considered 'ethical' (see e.g. Stilgoe and Farook, 2008). Patients tend to be more satisfied when they have an active role in considering and deciding about possible treatments. Sometimes this also leads to better health results (Jahng et al., 2005). The second argument for patient participation lies in the demographic and labour market developments in many western countries (see e.g., Commission of the European Communities, 2000). Because of an ageing population it is argued that a significant amount of health care tasks need to be carried out by patients and/or their family members (Van den Eerenbeemt and Mulder, 2005).

Still patient participation can also be 'unethical'. For instance, patients can be emotionally and mentally unable or unwilling to decide about their treatments (Bensing et al., 2004). Moreover, the extent to which patients appreciate an egalitarian

Table 1: development stages of EHRs and PHRs.

Stage	Electronic Health records	Personal health records
1. Computerizing	Computerized records	Hand written notes; personal written annotations, personal knowledge
2. Automating	Automated systems	Manual entry into pc applications (word, excel, electronic agenda). Stand-alone medical devices with computerized records
3. Connecting	Digital organizational infrastructure (e.g. hospital information systems)	Using medical devices and putting output of these devices into journal / ehr-application
4. Networking	Networked, distributed EHR	Automatic connections between devices and personal EHR, synchronizing EHR with EPR by hand
5. Converging	Virtual, multidimensional records on shared infrastructure	Automatic, multidirectional synchronization of PHR and EHR

relationship with a health care professional varies from patient to patient and from context to context (Bensing et al, 2004).

This implies that within every medical encounter doctor and patient face the challenge of distributing roles and responsibilities, depending on the specific context. We use the term 'Relational Responsibility' to refer to a process by which doctor and patient are responsive to each other's ideas, norms and values and thus try to create an optimal role division, depending on the specific context of their interactions (McNamee and Gergen, 1999). So for instance, sometimes patient and doctor both agree to a subject-object understanding of their relationship, in which the patient has a passive role. At other times, the patient will appreciate an active participant in his health care situation. This asks of the participants in doctor-patient communication to be open to each other's preferences. In this way a so-called 'soft' self-other differentiation *can* emerge (Hosking, 2007).

2 CHANGING INFORMATICS

So far we have emphasized the importance of differentiation in doctor-patient relationships. The next question is: Can developments in health care informatics support relational responsibility in the doctor-patient relationship? To answer this question it is useful to distinguish between two forms of health care informatics: consumer health informatics (PHRs) and provider-oriented medical informatics¹ (EHRs) (Eysenbach, 2000).

Personal Health Records (PHRs) can be seen as a form of consumer health informatics, because they are designed to empower patients by giving patients more access to health care information and in this way bridging the knowledge gap between health care professional (Eysenbach, 2000, Tang et al.,

2006). EHRs are manifold in appearance and traditionally support the health care professional, or its institution, to manage information *about* (not from) patients.

Table 1 shows the different development stages of medical recordsⁱⁱ. In more recent stages of information technology the interoperability, i.e. the degree in which it is possible to exchange information, has increased significantly. This means the fifth development stage, in which EHR and PHR converge, has become technically possible. Due to standardization and higher levels of interoperability, both information written by the patient and information written by the professional *can* be exchangedⁱⁱⁱ. Such a convergence of EHR and PHR would support relational responsibility because patient and doctor can, depending on the particular context of their communication, choose who adds information to the health record, at what times this information is read - and by whom.

Given this (theoretical) possibility of convergence it is interesting to empirically study whether countries are planning on realizing this convergence and for what reasons. Do policy makers acknowledge the need for differentiation in doctor-patient relationships (relational responsibility) and what is their perspective on health informatics?

3 EMPIRICAL APPROACH

The empirical work concerns a qualitative, explorative and comparative study, involving three countries. For each country we studied:

- the institutional context: How is the EHR implemented?
- EHR policy: What are the primary objectives of the national EHR?
- functionalities of EHRs: What are the most im-

Table 2: EHR policy: objectives of EHRs.

Canada	Denmark	The Netherlands
<ul style="list-style-type: none"> - Increasing quality of care - Timely access to accurate information and improved decision-making support - Enhancing ongoing disease management and longer-term care - A higher level of patient involvement and education¹ - Enabling patient self care/remote care - Controlling system risks from pandemics or other health issues - More guideline-compliant treatment - Manage wait times and improve patient access - Enhanced performance management of cost, quality and access <p>(Canada Health Infoway, 2005)</p>	<ul style="list-style-type: none"> - Enable the individual citizen to have safe access to personal health-related information - Increased efficiency - Quality assurance of health care delivery, e.g. by fewer errors in medication - Improved quality of clinical decision-making - Shorter waiting times - Supporting the citizens freedom of choice <p>(Ministry of the Interior and Health, 2003)</p>	<ul style="list-style-type: none"> - Continuity and quality of care - Decrease in number of avoidable medication errors - Increasing safety of patients - Increase in the efficiency of health care - More demand-driven health care, i.e. preventing patients from unnecessarily having to tell the same story over and over again <p>(Ministry of Health, Welfare and Sport, CIBG and NICTIZ, 2005 and 2008; Website of Ministry, 2008)</p>

- portant design features of the EHR and who can use them (professionals and/or patients)?
- data: What data are exchanged through the EHR and are these created by professionals and/or patients?

The answers to these questions are based on the study of policy and implementation documents.

4 EHR POLICY & DESIGN

4.1 Countries & Institutional Contexts

We have chosen to study the policy and design of EHRs in Canada, Denmark and The Netherlands, because these countries are actively working on a national, generic EHR, and because they have a high penetration of pc and Internet use. After all, convergence is difficult if only a few people use Internet. All three countries are in the top ten of the United Nations E-government Readiness Index (United Nations, 2008).

In Canada each province is creating its own EHR, which in time should become interoperable. Denmark and The Netherlands are working on one nation-wide, generic EHR.

All three countries have founded and/or appointed an implementation organization. In Canada the federally funded organization ‘Health Infoway’ is mandated to accelerate the development and adoption of EHR’s (Canada Health Infoway, 2005). Infoway tries to create the basic infrastructure that makes it possible to connect EHR systems and in addition tries to distribute successful EHR practices nationwide. In Denmark ‘Medcom’ is responsible for the creation of an interoperable ICT-

network and communication standards (Medcom, 2007). In The Netherlands the Ministry of Health, Welfare and Sport has appointed ‘NICTIZ’, the national ICT institute for health care. NICTIZ has developed a national ICT infrastructure for the health care sector (NICTIZ, 2005).

4.2 EHR Policy: Primary Objectives

The table below gives an overview of the primary objectives that follow from EHR policy documents^{iv}.

Canadian policy makers directly link the EHR to patient involvement, participation, education (empowerment) and self-care, which are considered important objectives. Danish government also makes a direct link between patient access to EHRs and their ability to actively participate in their healthcare process. In The Netherlands the formal EHR objectives are all oriented towards supporting providers in the delivery of health care. However, NICTIZ states in its brochure that it sees the EHR as a way to increase patient’s autonomy, to take work off health care professionals’ shoulders and to increase the level of responsibility and involvement (NICTIZ, 2005).

4.3 Functionalities of EHRs

Documentation (registration of health information) and collection (retrieval of health information) are the first functionalities that all three countries hope to realize. In addition to this, Canada hopes that in 2015 other functionalities like order entry, public visibility into wait times, Clinical Information Systems and chronic disease management will be available (Canada Health Infoway, 2005). Denmark connects the EHR to various telemedicine projects in

which the local nurse can perform certain activities that in the past only specialists were allowed to perform. In this way patients can be treated closer to home.

In both Canada and The Netherlands health care professionals first gain access to the EHR. The Dutch NICTIZ is exploring the possibility of giving patients access to their record through a patient portal, but in the first year(s) patient access is only possible by a paper print of the EHR (NICTIZ, 2005). The same applies to Canada: a patient portal with self-help tools and basic EHR information should be in place around 2015 (Canada Health Infoway, 2005). In Denmark there is already a patient portal in use, which is linked to the EHR infrastructure. At "sundhed.dk" patients can find a directory of names and addresses, make appointments, get prescription renewals, contact their GP through e-mail, compare prices, quality and accessibility of care, by drugs online, receive information about prevention and treatment, view information on waiting lists, preventive medicine, health laws and regulations and access their own personal health data, i.e. their EHR (Ministry of Interior and Health, 2003).

4.4 Data that are Exchanged

All data that are exchanged by the EHR infrastructure in the three countries are created and provided by the community of health care professionals. Patients do not have the possibility to add health related information to their EHR.

Within the basic Canadian infrastructure data that will be exchanged are: a) client and provider registries; b) Public Health Surveillance data (PHS); c) drug data; d) laboratory data and e) Diagnostic Imaging (DI).

For the most important data products in Denmark, almost all paper forms have been replaced by electronic forms. Hospital information and treatment plans are now sent electronically to municipal care centers (62%)¹. GP's receive discharge letters (88%) and send prescriptions (83%). Laboratories send lab results to GP's and hospitals (96%), after receiving lab requests (75%). Reimbursement is almost entirely done electronically (96%).

The first version of the Dutch EHR exchanges medication data and a GP's summary file that is to be used by the local GP. Within a couple of years NICTIZ also hopes to realize an emergency record, a diabetes record and it hopes to integrate laboratory data (NICTIZ, 2005).

5 CONCLUSIONS

In the first part of this paper we concluded that differentiation in medical encounters is needed. There are important ethical and practical reasons for patient participation, but sometimes a more traditional role division, in which patients have a more passive role, can be preferable. Depending on the relational context, patient and doctor need to look for an optimal role division. Health informatics can support such Relational Responsibility in doctor-patient relationships, given that increasing interoperability makes convergence of EHRs and PHRs technically possible.

We empirically explored what norms and values with respect to the role division between doctors and patients are being stabilized in nation-wide EHRs – both in policy and design. When we look at Canada, Denmark and The Netherlands we can first conclude that policy makers all to a greater or lesser extent emphasize the importance of patient participation. Canada has the most extensive vision on the EHR as a means of empowering patients and promoting self-care. When we look at the ways in which the EHRs are implemented, we must conclude that we can only find few traces of these visions on patient participation in the current designs of EHRs. Denmark and The Netherlands are ahead in realizing an infrastructure for the national exchange of medical information between professionals. In Denmark the possibility of patient participation is most developed through a patient portal that enables patients to access information written by professionals. However, in none of the countries patients can add medical information that is written by themselves to the record.

In none of the policy visions we find an explicit recognition of the need to facilitate a differentiation of role division in doctor-patient relationships. In addition, the integration of EHR and PHR is in no policy document, although Canada does plan on creating self-help tools for patients and the implementation organization in The Netherlands values the idea of patients adding information to the EHR.

In sum, for the upcoming years Electronic Health Records will mainly support one traditional role division: the one in which the health care professional is in the lead and is the better-informed party. Although the perspective on the doctor-patient relationship seems to be changing towards more patient participation, the current use of informatics still seems to be provider-oriented.

Future research could explore how these policies

and designs of national EHRs work out in practice and to what extent they restrict or support patient participation.

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ⁱ The word 'provider' refers to the health care professional.

ⁱⁱ The development of EHRs is patchy. Thinking in terms of configurations can therefore be useful, in which certain aspects of an EHR still belong to one of the former stages, whereas certain other aspects are already congruent with later stages.

ⁱⁱⁱ The choice for exchange and use of information depends on contextual factors such as quality, privacy and relevance.

^{iv} In Canada and Denmark one integrated vision document with both long-term and short-term objectives have been written. In The Netherlands we had to study different information sources to create an overview of objectives as formulated in formal documents.