

# EigenJournal: A personal collaborative medical journal

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**Abstract**—In today’s health care, a growing interest in more active patient involvement in their treatment is emerging. Along with the fact that electronic health records is now commonly used by most health care providers, a unique possibility to improve patient involvement through personal health records exists. This paper investigates the premisses under which a personal health record system is to be implemented. It furthermore suggests a conceptual architecture that can realise patient-centred care through communication with the patients, partnership and empowerment.

**Index Terms**—Medical services, personal health record, software architecture

## I. INTRODUCTION

AT its core, clinical practice is the application of knowledge, technology, expertise and skills to explore and explain medical problems (diagnostics) and to alter the course of a disease in a prognostic favourable direction (therapy). The outcome of a diagnostic process is a description of the disease as the explanation of the patients’ problem(s), what might have caused the disease and its prognosis. Therapy is about identifying the most favourable treatment, presenting the pros and cons of these for the patient, allowing him to make an informed choice, developing a treatment plan based on what the patient is willing to, and finally to execute the plan.

Internet and information technology have started to influence the physician-patient relationship, where “modern-day” empowered patients possess better knowledge and ability to reflect upon their own health situation and medical problems and thus acts to a lesser degree as mere passive receivers of therapy [1]. In general, these patients seek more convenience, control and choice and show a desire to become a more active partner in their own health [2].

In executing the therapeutic plan, we expect the active, informed patient to be able to take on several activities:

- The patient is the sole source of descriptions of his or her subjective experiences;
- The patient is his own observer;
- The patient is the sole source of his own hypotheses;
- The patient is the principal source of descriptions of his own actions.

We believe that it is possible to design a system that support the patient in these plan execution and monitoring activities and that such a system will enable patient education and better collaboration between patient and physician.

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The rest of the paper is organised as follows: First the background and motivation for a personal health record is covered; secondly, a description of how the EigenJournal fits into the current electronic health record environment is given; thirdly, an analysis of the conceptual architecture of the EigenJournal is carried out; finally, a description of the ongoing work, and pointers for future work is given.

## II. BACKGROUND AND MOTIVATION

With the growth in the amount of patients receiving treatment for a growing number of illnesses, it is becoming more and more important to improve the efficiency and impact of patients’ treatment. The three main actors in this improvement of treatments are: the patient, the health professional, and the society at large. This section describes the benefits and motivations for an EigenJournal from each of the three’s perspective. Figure 1 depicts the main benefits for each of the three actors.

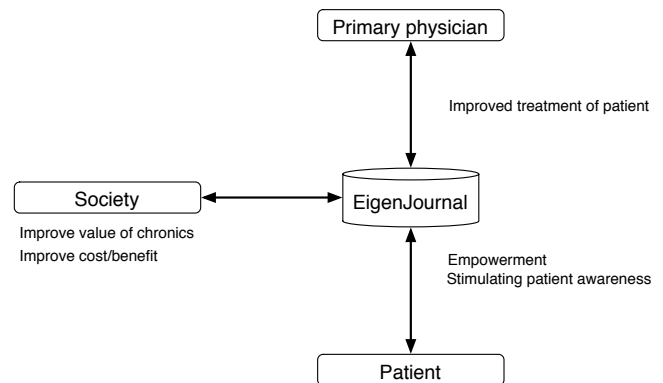


Fig. 1. Actors benefiting from EigenJournal

Coping with illness and undergoing therapy is a learning process for the patient. When a patient encounter an health professional, most often a physician, they not only bring along their symptoms and *own* observations, but also *their own* hypotheses, plans and actions. The physician uses this information, as well as the information from examinations, laboratory results, and the physician’s own skill and knowledge to infer hypotheses regarding the diagnosis. For many patients the diagnosis arrived at is perceived as a conclusion; one which the patient may choose to accept or ignore.

The physician has a paramount responsibility to explain why the diagnosis is plausible, and motivate the patient to comprehend why a given therapeutic plan is feasible. For

many patients both the diagnosis and therapy may appear to be complicated and difficult to understand; thus, a learning process is often required for the patient. This is especially important when interventions, such as medication, is required, as the patient has the final decision on which therapeutic plan to comply with. The patient's own interpretation of their situation, the diagnosis, and any therapeutic plan is of uttermost importance. Therefore, stimulating patient awareness and reflection on the effect of therapy, will have an educational effect on the patient.

For the physician, the ability to collect precise experiences from the patient's execution of a therapeutic plan will enable a better treatment.

In the last decade, methodological techniques have been developed to improve the reliability and accuracy of medication reports and other kind of self-reports from patients [3]. Recognising the shortcomings of recall and memory, patients are often asked to keep a medical diary, a personal medical record. For chronic diseases, where contact between doctor and patient may happen at regular but relatively long intervals, this is particularly important.

However, the collection of data by these methods has significant shortcomings. Many patients do not comply with maintaining the diary, or make a diary that is highly skewed towards excellent compliance: "I took the medicine just as you told me doctor" (C.S. Rand in [3]). How patients report is also highly dependant on the actual form of diary, i.e. the tool for keeping record, e.g. paper-based versus electronic [3]. Patients furthermore stop reporting because of unmet expectations for benefit of reporting and lack of feedback.

Chronic disease is a public health issue that could be addressed, in part, by increasing the ability of individuals to better manage their condition and its consequences on a day-to-day basis [4]. Patients that carry a chronic condition need to make qualified choices regarding treatment of their own condition. This makes educative health services as important as medical treatment, especially since patients generally do things in their best interests if they feel confident and, most importantly, get some support [5]. There is now a large body of evidence showing that educational interventions that enhance people's sense of self-efficacy can reduce the demand for medical intervention [6]. Stanford University's Chronic Disease Self-Management Program is one of these programs that prove reduced health care cost and may lead to increased quality of life [7]. Studies also show that online interventions can give effect [8]. These educative health services emphasise processes that allow the patients to draw inferences from the experiences of both other patients and health care professionals. A health related educative service should increase the patient's ability to interact with his surroundings, in a way that leads to better maintenance of health than could be done without the service.

### III. EIGENJOURNAL IN CONTEXT

In the Norwegian health care sector today, most actors have implemented an Electronic Health Record (EHR) system [9], and all health care providers are required to document all patient encounters and interventions in a medical record.

However, the level of electronic exchange of medical information is low. Most communication still takes place on paper. The Norwegian directorate for health and social affairs has launched a sequence of strategic plans to target this [10]. Initiatives include the development of secure health care networks, development of standard messages for specific information such as discharge summaries, referrals, requisitions and electronic prescriptions and the development of a so-called "Kjernejournal" [11] (see Figure 2).

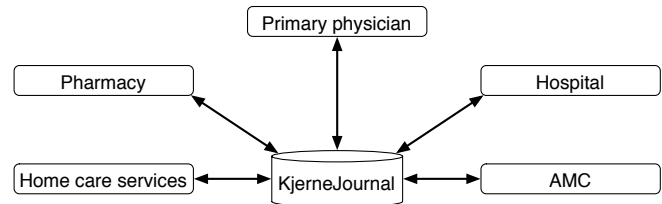


Fig. 2. Kjernejournal

The Kjernejournal is a server containing the "core medical information" for a patient that resides outside the boundaries of the existing health care entities/providers and their local EHR systems, but where all providers can access and update this information given the patient's consent.

The "Kjernejournal" server is to some extent a step towards our proposed EigenJournal server, in the sense that it supports collection of relevant medical information for the patient. However, as we see it, this solution only covers some of the aspects needed to support the active, empowered patient:

- The information in the Kjernejournal is mere excerpts or copies of the documentation given by the health care providers, the health care providers are the legal owners of this information, even if the patient are entitled by law to view this information. As such, the Kjernejournal is a mere collection of selected information intended to support information exchange between health care providers and not actively engaging the patient in the information loop. In principle, the patient does not have a system for accessing information in this server.
- Information in the kjernejournal, as copies of provider-specific documentation, is not prepared or provided in a way that makes it readily accessible, readable and understandable for the patient. No attempt is done to present the contents of this journal in a way that explains, motivates or educates the patient.
- Furthermore, without any access to the Kjernejournal, there is no room for patient provided information. The patient cannot enter his own "stories", experiences with therapy, symptoms, observation nor comments to the medical information.

So, while the Kjernejournal solution offers support for mobility of patients through improved access to shared medical information, it offers little in direct support for the patient that desires to take control over his own therapy and actively participate in treatment, choose among different therapy plans or health providers.

The "Guardian Angel" concept, proposed by [12], [13],

takes on a different view. They propose “a fundamental shift” away from the local information systems residing at each health care provider, and into a system (the Guardian Angel) that “integrates over a lifetime all health-related information about an individual . . . thus providing, at minimum, a comprehensive medical record”. The Guardian Angel is not intended to support mere passive collection of information, however, it is intended to enable the patient with support for monitoring of health conditions, customising therapy plans, providing patient education functions through access to appropriate medical encyclopedias and explanations of diagnostic findings, i.e. to become a complete system in support of empowered patients.

While the Guardian Angel concept is a very powerful proposal, that actually covers several of the features we are looking for in the EigenJournal system, we believe that the wholly individualistic approach has some shortcomings, and to some extent contrary to Norwegian and Scandinavian conditions. Taking an extreme view, we might say that Guardian Angle places all of the responsibility for life-long medical information management and treatment monitoring on the patient himself.

Questions arise for those patients not capable of assuming such a responsibility, either because of their health situation or because of their level of computer literacy. Even the computer-literate patient could find this too much of a responsibility, and exposing him to a complexity that is unwelcome. Taking full responsibility for collecting, storing, and restricted sharing of own health information is a daunting task.

The individualistic view taken in the Guardian Angel solution, to some extent assumes that the patient is free to choose from a “market” of independent health service providers, while in most Scandinavian countries the public health care services are the dominant providers. Even if given the freedom of choice to select among hospitals, primary physicians and various private clinics, most Norwegian patients “follow the path” laid out by different entities in the public health care.

The execution and monitoring of therapy plans is to some extent a dialogue between physician and patient, where the overall responsibility as to the medical underpinnings of the diagnosis and the soundness of the plan and the observations and the responsibility to take corrective actions lies with the physician or the health care provider. We are looking for a system that not individualises the patient, but rather strengthens the patient’s position in the dialogue with the physician and offers improved collaboration between patients and health care providers. potential, other health care providers; i.e. the health record. This, along with the information supplied by the patient facilitates the construction of therapy plans.

Definitions of Patient Centered care [14], [15], [16] stress the development of the patient-physician relationship into more of a partnership, the enhancement of the communication between the two as well as the ability of the physician to take into account a holistic view of the patient’s health situation, “beyond the current problem”. One important element of this is by “exploring the experience of disease and illness: patients’ ideas about the problem, feelings, expectations for the visit, and effects on function.” [14]. In the EigenJournal system, this is what we have denoted “Patient Stories”, and we believe

that it is important for the EigenJournal system to be able to capture such stories and utilise these in the patient physician communication, i.e. to support patient diaries and self-reports.

To summarise, the context of our EigenJournal system is laid out by the Norwegian “KjerneJournal” project and its position as a tool for information sharing among actors in the Norwegian public health services, but as pointed out, this solution does not currently support the patient or enhance the patient-physician communication. For this we have to adopt solutions found in patient centered medical information systems and solutions for patient-centered care.

#### IV. CONCEPTUAL ARCHITECTURE

As was described in the introduction, clinical practice is the application of knowledge, technology, skill and expertise to diagnose a disease, and treat it. Furthermore, part of the knowledge about the patient is registered in medical documents from, potential, other health care providers. This information, along with the information supplied by the patient lead the health care professional to construct therapy plans.

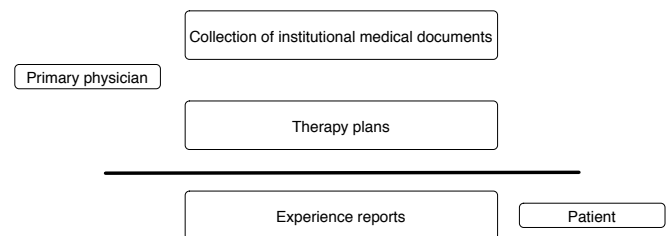


Fig. 3. Boundary between ownership of information

Figure 3 depicts how the primary physician constructs and maintains both medical documents and therapeutic plans. The ability to produce and alter medical documentation is solely in the hands of health care professionals. Whereas, information produced by the patient is, by nature, solely in the hands of the patient. However, patients are, on a general basis, allowed to read documents, and health care professionals can be allowed access to the information produced by the patient. The black line in Figure 3 represents a border which information only can cross in a *read only* manner. This very strict ownership of information is paramount in health care.

As described in Section III, the Kjernejournal is designed to facilitate the exchange of information between different actors within health care. However, it does not support dissemination of medical documents to the patients.

The ability to disseminate medical documents to the patients, thus allowing the patient a more active role, can be approached in two different ways.

The first, and initial obvious, way is to allow the EigenJournal to be an integrated part of the Kjernejournal. Figure 4 shows how the EigenJournal is integrated with the Kjernejournal. This would enable the patients to execute his right to read the documents contained in his medical journal. However, at least two main obstacles stands out when attempting to use this approach. First, and foremost, as the patient is allowed, and expected, to contributed to the

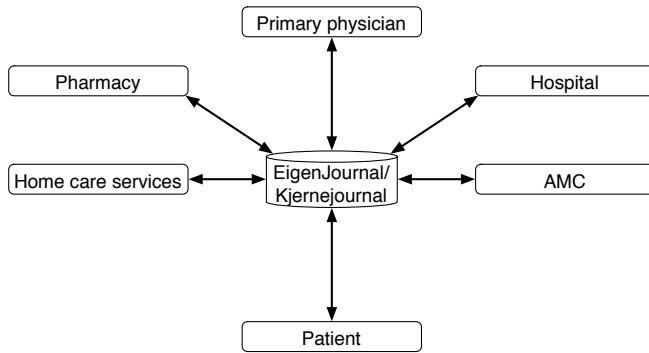


Fig. 4. The context of the eigenjournal system

EigenJournal, resulting in the fact that the information contained in the journal will no longer be sanctioned by the health care professionals, thus not necessarily applicable as documentation for later treatment. Recall the fact that even though patients generally has the right to read and use medical documentation, only the health service can produce and alter medical documentation (See Figure: 3).

Secondly, health services, on a general basis, should only be allowed access to relevant information, and has an obligation not to disclose any information acquired about patients to third parties. If the information that has been contributed by the patient were to be an integrated part of the Kjernejournal, it would be hard to determine who would have access to what written by the patient.

However, as the Kjernejournal is not only a good idea, but also something which is currently under development, the EigenJournal must be regarded as a supplement to this. Looking at Figure 5, an architecture that maintains the fixed boundary between the different ownership of information, yet allows for an integration between the Kjernejournal and the EigenJournal.

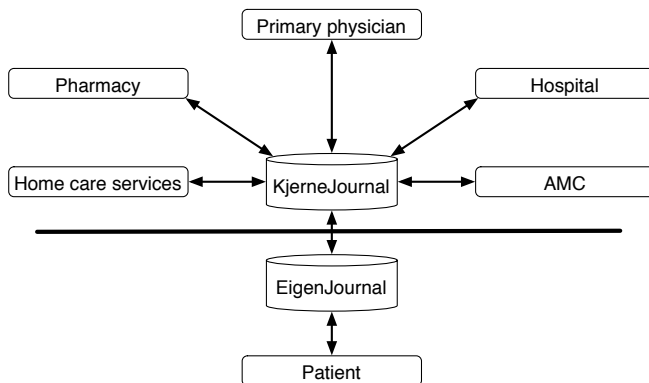


Fig. 5. Kjernejournal and EigenJournal

This architecture allows for the sharing of medical records between health care providers. As an addition it allows for a simple and efficient method for the patient to acquire access to his medical records. Furthermore, with the boundary left intact, the development of the Kjernejournal can continue in parallel with the development of the EigenJournal.

## V. PRINCIPLES FOR CONSTRUCTION AND CONTENT

### A. Kjernejournal

At its core, the Kjernejournal is in essence a secure archive of medical documents. The document model for medical information is prominent in Norwegian EHR systems and information exchange. According to the Norwegian standard [17], EHR information is structured according to *document folders*, *documents* and *document fragments*, where a document “is the central component in the record, and is always registered and signed as a whole”. However, a document is constructed from document fragments that can have a structured data content definition, with coded and well defined data elements. The Norwegian standardisation body (KITH<sup>1</sup>), is currently working on such structural content standards for several specific fragment types. A selection of these will be implemented in the final Kjernejournal system.

For information exchange, the Norwegian standard [18] will define messages based on XML content embedded within an ebXML [19] framework to ensure unique identification of sender and receiver and provide a transaction mechanism to ensure proper transfer of the information, including receipts and error messages.

### B. Therapy plans

While the Kjernejournal can collect and store all documentation from health care providers, this information is mainly written both by and for health professionals and not always easily accessible for the patient. According to Norwegian regulations, patients are not only entitled to access this information, but also to get proper explanations of its content. Furthermore, patients with a complex disease that requires long-time care and involving several health care providers are entitled to have developed an individual plan, outlining the goals, timeline, resources, etc. for the therapeutic actions to be carried out.

We believe that a major challenge for the EigenJournal system is to become a vehicle for the physician, where he can provide patient-centered information about the diagnosis and plan, explained in a manner, which the patient can relate to and understand, and which clearly and explicitly states goals and actions. Another important challenge is to be able to present this information to the patient in a manner that makes it usable in the daily therapeutic activities the patient has to undergo. The patient-centered plan will have to serve several purposes for the patient; form an explanation of the actions to be carried out, explain purposes and motivations as well as provide reminders of actions to ensure compliance.

### C. EigenJournal and “Patient-stories”

The above parts of the EigenJournal contain information provided by health care professionals. The last part, the Personal Medical record will contain the information provided by the patient, the “patient-stories”. This is where the patient can keep his diary, containing comments, notes and more specific reports, for given elements of the therapeutic plans. Two principles govern our work in this area. First, we would

<sup>1</sup>Norwegian Centre for Informatics in Health and Social Care

like to organise the reports according to the plan, so that it is possible to detect and note discrepancies between the initial planned action and the actions actually carried out. Detection of such discrepancies is important for the patient's awareness and learning and is also important information for the physician to take corrective action if the plan does not work out. Second, we would like to distinguish between the reporting of action and the reporting of the patient's subjective experiences. By subjective experiences, we refer to the patient's own observations, hypotheses and experienced effects and side-effects.

## VI. ONGOING AND FUTURE WORK

This is ongoing work, as we are currently investigating different implementational issues.

Personal Health Record (PHR) systems have received much attention recently, in particular in the USA, where the secretary of Health and Human Services, the National Coordinator for Health Information Technology, and the Administrator of the Centers for Medicare and Medicaid Services, have all identified PHRs as a focus area. A PHR is defined as "An electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorised, in a private, secure and confidential environment." [20]

There are two existing implementation bases, which are currently under investigation: The PING<sup>2</sup> project [21] from Harvard Medical School, MIT and Children's Hospital Boston; and the openEHR<sup>3</sup> project from University College London and Ocean Informatics.

The PING project is an attempt to implement a personally-controlled health record, which has evolved from the Guardian Angel concept that was described in Section III. The system is currently implemented in the Java language and serves users through web services.

The PING project assumes a wholly individualistic approach, and as described in Section III, we currently believe that it has some shortcomings and to some degree is contrary to the health care system in Norway. However, some of the ideas about how distributed medical documents can be linked together, the focus on exchange of data through public standards, and the methods for allowing access to data might be beneficial for the EigenJournal.

The openEHR project wishes to construct formal specifications for representation and communication of electronic health record information. In particular, openEHR supports the implementation of distributed, patient-centred and shared health records. We are currently in the process of investigating the feasibility of using openEHR to realise the Eigenjournal.

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## REFERENCES

- [1] S. J. Williams and M. Calnan, "The 'limits' of medicalization?: modern medicine and the lay populace in 'late' modernity." *Social science & medicine*, vol. 42, no. 12, pp. 1609–1620, June 1996.
- [2] M. J. Ball and J. Lillis, "E-health: transforming the physician/patient relationship." *International Journal of Medical Informatics*, vol. 61, no. 1, pp. 1–10, April 2001.
- [3] A. A. Stone, S. Shiffman, J. E. Schwartz, J. E. Broderick, and M. R. Hufford, "Patient non-compliance with paper diaries." *British Medical Journal*, no. 324, pp. 1193–1194, May 2002.
- [4] J. H. Barlow, G. V. Bancroft, and A. P. Turner, "Volunteer, lay tutors' experiences of the chronic disease self-management course: being valued and adding value." *Health Education Research*, vol. 20, no. 2, pp. 128–136, 2005.
- [5] K. Lorig, "Partnerships between expert patients and physicians." *Lancet*, vol. 359, no. 9309, pp. 814–815, March 2002.
- [6] A. Coulter, *The autonomous patient : ending paternalism in medical care*. Nuffield Trust, 2002.
- [7] K. R. Lorig, D. S. Sobel, P. L. Ritter, D. Laurent, and M. Hobbs, "Effect of a self-management program on patients with chronic disease." *Effective Clinical Practice*, vol. 4, no. 6, pp. 256–262, November 2001.
- [8] K. R. Lorig, D. D. Laurent, R. A. Deyo, M. E. Marnell, M. A. Minor, and P. L. Ritter, "Can a back pain e-mail discussion group improve health status and lower health care costs?" *Archives of internal medicine*, vol. 162, no. 7, pp. 792–796, April 2002.
- [9] H. Lærum, G. Ellingsen, and A. Faxvaag, "Doctors' use of electronic medical records systems in hospitals: cross sectional survey." *British Medical Journal*, no. 323, pp. 1344–1348, December 2001.
- [10] *S@mspill 2007 Elektronisk samarbeid i helse- og sosialsektoren*, The Directorate for Health and Social Affairs, 2005.
- [11] T. Nystadnes, "Løsningskisse fyrtårn Trondheim: Legemiddelopplysninger i Samtykkebasert kjernejournal," Norwegian Centre for Informatics in Health and Social Care, Tech. Rep. 29/05, 2005.
- [12] P. Szolovits, J. Doyle, W. J. Long, I. Kohane, and S. G. Pauker, "Guardian angel: Patient-centered health information systems," Massachusetts Institute of Technology, Laboratory for Computer Science, Tech. Rep. TR-604, 1994.
- [13] P. Szolovits and I. Kohane, "Against universal health-care identifiers." *Journal of the American Medical Informatics Association*, no. 1, pp. 316–319, 1994.
- [14] P. Little, H. Everitt, I. Williamson, G. Warner, M. Moore, C. Gould, K. Ferrier, and S. Payne, "Preferences of patients for patient centred approach to consultation in primary care: observational study." *British Medical Journal*, vol. 322, no. 7284, p. 468, February 2001.
- [15] M. Stewart, "Towards a global definition of patient centred care - the patient should be the judge of patient centred care." *British Medical Journal*, vol. 322, no. 7284, pp. 444–445, February 2001.
- [16] A. E. Bauman, H. J. Fardy, and P. G. Harris, "Getting it right: why bother with patient-centred care?" *The Medical Journal of Australia*, vol. 179, no. 5, pp. 253–256, 2003.
- [17] T. Nystadnes, "Ej standard: Arkitektur, arkivering og tilgangsstyring," Norwegian Centre for Informatics in Health and Social Care, Tech. Rep., 2001.
- [18] E. S. Seland, "Rammeverk for elektronisk meldingsutveksling i helseteansen," Norwegian Centre for Informatics in Health and Social Care, Tech. Rep. 25/02, 2002.
- [19] *ebXML Requirements Specification Version 1.06*, ebXML Requirements Team, May 2001.
- [20] *Connecting for Health. The personal health working group final report*, Markle Foundation, July 2003.
- [21] W. W. Simons, K. D. Mandl, and I. S. Kohane, "The ping personally controlled electronic medical record system: Technical architecture." *Journal of the American Medical Informatics Association*, vol. 12, no. 1, pp. 47–54, October 2004.

<sup>2</sup><http://ping.chip.org>

<sup>3</sup><http://www.openEHR.org>