

# Patient Relation Management: a relevant solution to connect the links of a healthcare chain

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## Abstract

*The USIT-tool is used to investigate the health care chain of Multiple Sclerosis (MS) in a Dutch region. The advantage of the USIT-tool is that it results in insight in the relevant problems, solutions and constraints of the caregivers both in the organisational and the information technological area. The main problem in the MS-health care chain proved to be the lack of co-ordination and the inefficient communication between caregivers. Although most caregivers were convinced of the need to improve delivered care for MS-patient, most of them also expressed that they would spend little time and energy on improving MS-care, because of the low relevance of MS-care compared to other kinds of care. To improve care, taking in account this constraint we propose to build a Patient Relation Management (PRM) System. A PRM is a simple web-based application that is based on agreement by the caregivers about the route an MS-patient should follow through health care. PRM supports routing, tracking and tracing of a patient and supplies the caregivers with professional guidelines. The PRM-concept can easily be expanded to other patient groups or diseases and can serve as a first step to a regional Electronic Patient Record. It is likely that we would have suggested a far more complicated ICT solution if we had only analysed the MS-care process as such, without specific consideration of the USIT dimensions. The USIT analysis helped us to balance the breadth of the proposed solution with the nature of the situation the future users of the system are in.*

## Keywords:

Electronic Patient Record, USIT, Patient Relation Management, Health Care Chain, Multiple Sclerosis.

## 1. Introduction

Several papers on tools to reveal the user's requirements or tools to stimulate user participation in the development of information systems in health care have been published the previous year [1] [2] [3] [4]. These tools usually focus on a fit between the developed system and the user on one aspect of innovation-diffusion. The USIT-tool comprises four diffusion aspects: relevance, resistance, requirements and resources [5] [6].

Table 1 shows the measured dimensions related to the diffusion aspects. The dimensions are measured using structured interviews.

In this way a more precise insight can be gained about the nature and relevance of problems and of possible solutions. These solutions can be organisational changes, IT-related or both. Also a better view of constraints and prerequisites can be established. This insight is especially needed when resources are limited and choices have to be made which problems will be solved and which will not.

Table 1- USIT-tool

Diffusion aspect	Dimensions
Relevance	General relevance Micro-relevance Compatibility to current way of working
Resistance	Permission to change Attitude to change Compatibility to ability to change
Requirements	Functional capability Ease of start-up Ease of use
Resources	IT availability Support functions

Many scientists and workers in health care presume that a future regional or national Electronic Patient Record (EPR) could make a major contribution to the improvement of the quality, efficiency and efficacy of delivered care. In previous research we introduced the orientation-model to categorise EPR-projects according to their origin combined with four factors of success. These factors of success are: relevant to the end-user, integrated and complete patient data, available to all caregivers, and containing active elements. To meet these four criteria of success an EPR must cross the borders of its orientation [7]. The importance of a well-designed architecture and the use of standards is stressed by Van Ginneken [8] and Stegwee [9]. Although some promising developments exist, it is also clear that such an EPR will not be available in a short time to every local caregiver.

In this paper we do not wish to debate such considerations regarding the EPR. Also, it is true that a future EPR will support workers in the health care field to an extent that is not yet experienced. At the same time, future IT applications in healthcare will have to fit to local conditions. In this paper, we present a case in which we used the USIT-tool to elicit the local problems, constraints and possible solutions and where we propose a solution that meets these constraints. At the same time, we have proposed a solution that can also serve as a first step towards an EPR.

## 2. Research methods

The special challenge of the research is to find a solution that is locally, practically applicable and that can serve as a base for a more general, broader solution on the same time. This challenge is represented in the two research-questions, which are formulated as follows:

- In what way does an improvement of the information-services in the healthcare chain contribute to the improvement of the quality of care for patients with multiple sclerosis?
- How should a solution look like that solves the local problem but that also aligns with knowledge and standards on EPR and serves as a first step or building block of an EPR?

To answer these questions 17 caregivers, which are part of the MS-care chain in Twente, a Dutch region, are interviewed with the preliminary version of the USIT-tool [5]. Also 6 of the approximately 500 patients are interviewed to get an impression of how they experienced the given care.

### 3. Result of the MS-healthcare chain research

The main problem proved to be the lack of co-ordination in the health care chain. There hardly was a chain. We found handovers between caregivers that were executed by the patient himself. Patient-flow / workflow was not organised for the specific patient group. Two co-ordination mechanisms could be found: the official referral system and informal communication (mutual adjustment). The first one was very insufficient, because it does not cover all the information needs and because the key-role is destined for the GP, who is –in practice- too busy to fulfil his role as co-ordinator of care. The second is reasonably effective, but not very efficient and often slow. Not all healthcare providers are aware of the service that other caregivers can provide.

The USIT-tool also made clear that MS-care is not very relevant for most caregivers. That is to say, caregivers have high compassion to MS patients, but most caregivers saw only now and then an MS-patient. MS-care was really relevant for the few caregivers who spend a substantial part of their time on those patients. Because of this infrequent contact with MS-patient the knowledge of caregivers about MS-care seems to be insufficient. This lack of knowledge caused the next problem: incidents of insufficient and inadequate care, reported by the patients.

Other results from this research were: The shape of the health care chain for this chronic progressive illness proved to be a complex network with many cross-relations, which did not match with the formal referral tree. It is not a great surprise that patients and caregivers get lost or stuck in this spider-web, although patients felt these problems to a lesser extent than caregivers.

#### Constraints and prerequisites

There is no regional Electronic Patient Record or likewise IT facility in the area studied that could serve as a basis for solutions. Some caregivers use electronic records, but these systems are often used for administration purposes only and limited to the use in one institution. Almost all caregivers have (or would have in short notice) access to e-mail or the Internet.

Since the relevance of MS-care is only high to a few caregivers, most caregivers could not spend much time and effort in implementing a specific solution for MS-care. They fear to be loaded with separate solutions for every separate chronic disease. This means that solution to the problems in MS-care has to meet the following constraints: 1. No isolated solution for MS-care: a specific solution must be expandable for other diseases, 2. Implementation and maintenance must take very little effort and costs and 3. The solution must adhere to the present conditions.

### 4. Patient Relation Management

Several interviewed caregivers considered a regional EPR as the solution to the problems in MS-care, although a rather unrealistic one. The main benefits of an EPR would be to know who is involved with what patient and to have access to the necessary information without being dependent of other caregivers such as the GP as ‘pass on-desk’ of information.

This function of an EPR is not specific for MS-care, but wanted for all chronic illnesses and complex care. However realising a regional EPR demands much more effort, time and expenses than is available for improving MS-care. That is why we suggest building a Patient Relation Management (PRM) system, which can serve as a first step to accomplish

a regional EPR. We first describe PRM applied to MS-care, but it can be expanded to other health care chains.

This PRM consists of a web-based patient routing system, based on an agreement of the caregivers in the region on patient-flow. In this agreement the nurse specialist should play a central role as co-ordinator of care. But to fulfil this co-ordinating role support is needed. First agreement has to be accomplished about the routing of a patient through the healthcare chain when the patient is diagnosed MS. Secondly a system like PRM is needed, that contains the information needed for routing and co-ordination and visualises the actual "location" of the patient in the healthcare chain. When a patient is reported to the system a message will be sent automatically to those caregivers, which should be informed. The information in the system comprises the names of the reported patients and the names and functions of the caregivers that are or have been involved with the treatment of the patient and the likely next steps (caregivers) in the treatment. PRM does not contain medical data of the patient and does not substitute the patient records from the various caregivers. The system is part of a web-site that contains general information on MS and medical guidelines for caregivers.

PRM supports the organisational solution of the main problem of the caregivers by making the agreed guidelines and patient-flow available, easy to maintain and enriching it with knowledge caregivers need. They know to whom they should refer the patient and which caregivers can be asked for more information about the patient. We think that the effort it takes to report a patient to the system is rewarded by the more efficient communication that results and the information the caregiver can retrieve about the treatment of the patient. Many caregivers, which seldom see an MS-patient, lack this knowledge.

To be a building block of an EPR, PRM must be designed and built according international standards. Its architecture has to be open and transparent to make linking possible to different information systems, such as EPR or HIS in different institutions. Since PRM contains information of patients and caregivers, security is important.

## 5. Discussion

PRM is not an EPR. The main advantage of PRM is that it is a simple, inexpensive solution to present problems experienced by local caregivers, which does not create a new island of automation. Neither does PRM prohibit the development and implementation of an EPR. On the contrary we think that PRM can pave its way. PRM stems from the care process orientation, but could also be applied in the medical technology or administration orientation [7]. To be successful, an EPR must be relevant to the end-user, must present all patient data in a integrated way, must be available to all relevant caregivers and contain active elements. To meet these criteria an EPR must cross the borders of its orientation [7]. PRM does not offer all this. In a sense, it fails on the second EPR criterion and its activity is limited to notifying caregivers that a patient, whom should be seen, is reported. Further analysis would be needed after the introduction of PRM to clarify which design of a regional EPR could have added value.

## 6. Conclusion

Existing tools to identify processes and interviews with future users are common ways to map the conditions where IT solutions can be applied in healthcare. We learned from this

research that the USIT analysis of the characteristics of the end-user helps to provide a more appropriate picture of the problem and the constraints and prerequisites for solving it. It is likely that we would have suggested a far more complicated ICT solution if we had only analysed the MS-care process as such, without specific consideration of the USIT dimensions. The USIT analysis helped us to balance the breadth of the proposed solution with the nature of the situation the future users of the system are in. Using information technology to improve the quality of care does not automatically mean implementing an EPR [10]. Less complex possibilities, like PRM are possible without creating new islands of automation.

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