

A smart service for the rheumatological care: Healthcare platform RhePort.de

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Abstract

The goal of the paper is to illustrate an innovative approach of the rheumatological care through smart digital services on an online platform and the establishment of a cross-sectoral network. The online platform RhePort.de will allow earlier diagnosis and treatment of rheumatic diseases, by which the quality of patient treatment will be increased and costs for the healthcare sector significantly reduced. The service platform is currently operating and being evaluated in the German region of Aachen, Dueren, Heinsberg and Moenchengladbach in order to prove increased effectiveness and efficiency of IT-based rheumatological care.

1 Current situation of rheumatic diseases

1.1 Background

Today, there are more than 100 different known symptoms of rheumatism worldwide, causing pain and functional disorders of the human locomotor system. Rheumatic diseases significantly burden the patients as well as the society. About 2% of the population is affected and the economic costs of rheumatic diseases are significant. On average 76% of female patients are declared incapable for work 8 days per month in the first year of illness. 25 - 42% of the patients are retired early during the first four years of a disease, a value that increases to 43 - 85% during the following years (Mau 2004). An early medical treatment may reduce the work disability (ter Wee et al. 2012). The later a treatment begins, the more difficult it is to individualize it to specific patients, resulting in tremendously increased costs. From a societal perspective, the annual indirect costs through lost productivity add

up to about 11.222 € per person each year. Additionally, the costs for medication amount to 20.000 € and the costs for the health care system to 4.170 € each year (Boonen et al. 2011; Mau 2004). Even higher costs are possible through surgeries and consequential treatments, which are not included in these numbers yet.

1.2 Problem statement

Rheumatic diseases are often diagnosed in an advanced state. Due to ambiguous symptoms and long waiting times for consultation of a rheumatologist, the entire process takes too long (on average more than 1.1 years from the very first symptoms to a final medical diagnosis). Most serious and irreparable damages occur in the earlier stages of the disease and especially to women (Westhoff, Edelmann, Zink 2009). Many inflammatory rheumatic diseases are - although not curable - treatable nowadays. The earlier the treatment begins, the better are the chances to reach a state, which is similar to a cure of the disease (Schneider/Krueger 2013). Personal consequences of rheumatism could be prevented or at least be reduced and follow-up costs of the therapy could be decreased. For instance, more than half of the cases of rheumatoid arthritis can be stopped with today's options of treatment (Puolakka et al. 2004).

Common reasons for a delayed diagnosis and inadequate treatment are the limited level of awareness of rheumatism, the specific symptoms and consequences of the disease, the often delayed medical care due to lack of specialists, the insufficient prioritization/organization of the medical referral to a specialist, and discontinuous long-term care.

Despite the need for easy assessment, rapid appointment scheduling, precise diagnosis and efficient patient-centered treatment, today's health and patient care system is dominated by horizontally aligned "silos" for physical and digital service provision. These closed systems prevent cooperation between the stakeholders on the cost of the patient. (Kagermann et al. 2015; Kaplan 2015; Bates et al. 2010). IT- based health care is a promising approach to address these problems.

2 IT-based healthcare services

Connected healthcare service platforms enable improved diagnostics and patient-care through the generation of Big Data and the utilization of individual patient treatment. Furthermore, easy and secure data-sharing across the healthcare ecosystem enables patients, insurance companies and doctors to exchange information efficiently and collaborate in real-time (Kagermann et al. 2015). In doing so, the information flow is improved between different stakeholders within the patients care pathway (Görlitz, 2014). This environment is simultaneously a fertile soil for the establishment of additional providers that offer specific knowledge (i. e. the evaluation of X-ray-images) as a service to the relevant stakeholders (Kagermann et al. 2015).

An IT based Community seems to be a promising approach in order to use available resources efficiently, to transform tacit knowledge into tangible knowledge as well as to realize a modern network of supply structures. Within the discipline of rheumatism, there are no known established IT-based based communities, which focus on the improvement of early diagnosis. Besides Scheibe et al. (2015), who developed an electronic referral system, which focuses on the use of pre-consultation exchange of information through IT support systems. Moreover, the mobile application of Rheumabuddy.com assists patients on tracking treatment information of the disease itself in a diary (e.g. pain barometer), but these services are not connected to physicians. The deficits of a missing IT-based approach to improve early diagnosis of the disease will be addressed by the RhePort.de platform in an innovative and patient-centered way.

3 RhePort.de as a digital marketplace for rheumatism care

For these reasons the development of RhePort.de - Rheumatism Portal of the 21st century system - was sponsored by means of the European Union (Ziel2-Program) and the Ministry of Health, Equalities, Care and Ageing (MGEPA) of the state North Rhine-Westphalia. Enabled by platform technologies, the objectives of RhePort.de are to:

- diagnose the illness during an early stage, start therapy quickly and effectively and establish a coordinated acute-management to minimize the activity of the rheumatic disease,
- minimize the physical and mental interferences and avoid consequential damages,
- limit the high financial burden on the health and social care system, e. g. by avoiding expensive therapies during a difficult and severe course of the disease, limit incapacity to work and early retirement,
- indicate the gender specific effects of the rheumatic disease, apply adequate therapies and help patients to reduce negative consequences.

The online platform RhePort.de is based on two pillars (see Figure 1). Patients as well as primary care providers are able to use **RPAS** (Rheumatism Patient Assistant System) in order to receive general information, concerning the record of symptoms and discomfort to provide a direct diagnostic screening. Based on obtained knowledge and a developed algorithm, an allocation service quickly forwards patients to a rheumatism specialist within the local network. Comprehensive information about the patients completes the service.

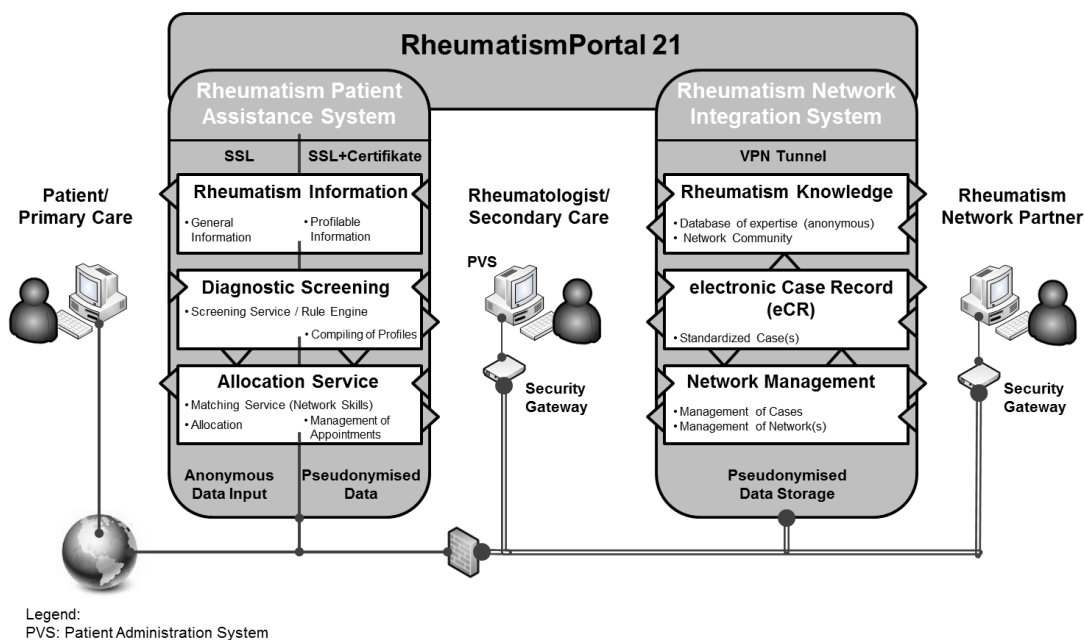


Figure 1: Schematic representation of the platform RhePort.de

Simultaneously, with **RNIS** (Rheumatism Network Integration System) the workflow and cooperation within the local network is improved. Substantial elements of the project were the development and deployment of an electronic Case Record (eCR), as well as a comprehensive support for the Community Management, especially for problems concerning rheumatology. Furthermore, a database about rheumatism knowledge was established. Medical examination and therapy methods are being discussed and agreed on by rheumatism experts. The upcoming paragraphs will describe the three main elements of RhePort.de briefly.

Diagnostic Screening: The screening function is a standardized, understandable and interactive procedure to record symptoms and discomfort (symptom guide). A questionnaire was developed as a self-assessment-tool by a working group of various rheumatologists, which is used to support the diagnostic and which is accessible to all patients and primary care providers for free. The online questionnaire and tool support systematic prevention as well as the early diagnosis screenings. During an interactive dialogue with the physician, the information is also used for medical assistance and appointments on-site.

Allocation Service: Based on the questionnaire, the patient is allocated into one of three categories, which shows the probability of the disease (e.g. group of patients with very high risk of rheumatoid diseases, group of patients without rheumatoid diseases, group of uncertain patient cases). In case of suspected rheumatism disease (or unsure cases), the patient automatically receives a list of short-term appointments for a rheumatism specialist (matching service) online, from which the patient can select an appointment. Parameters such as urgency, appointment availability and location of the patient are taken into account. Therefore a fast, early and valid diagnosis followed by an adequate therapy is achieved (appointment within 48 hours). First results show that the speed of the diagnosis is improved dramatically by this allocation service compared to the status quo in the German health care system. Based on the registration with only an email-address and a telephone number, only anonymized patient data is available. The possibility to add and publish additional health care data anonymously, taking the data

protection into account, is very important for the RhePort.de concept. For this reason a security architecture is implemented (e. g. methods of pseudonomic encryption, authentication, authorization and performance assurance), which focuses primarily on specifications of eCR (electronic Case Record) and KV-SafeNet (interface of the association of panel doctors).

Electronic Case Record: In order to improve the collaboration and procedure of the various treatments within the rheumatism network, the development and implementation of a rheumatism specific medical electronic case record, consistent with the eCR standards, is crucial. Under consideration of scientific quality standards, eCR consistent pseudonomic medical case records were created. Only authorized rheumatology specialists within the network can access this data. A case record contains patient information concerning diagnosis, therapy and progress of the disease. The documents are developed for the RhePort.de community and all medical partners are connected to the online community.

The main characteristic of multi-sided communities is to connect different, but dependent groups of clients with each other. The creation of additional value between those groups is the main idea of Rheport.de. Among an automated appointment and an electronic case record system, the community also distributes various information to patients on one side and physicians on the other side. Thus, network effects are crucial for this approach. The more participants are registered, the more value can be gained.

4 Discussion and outlook

After going live in February 2015, first results of RhePort.de could be evaluated successfully. At the time of November 2015, voluntarily there are 32 physicians connected to RhePort.de from the above mentioned region. Within the first nine months 464 patients registered on the platform with over 460 allocated appointments at the rheumatologist. A first evaluation shows that approximately one third of all allocated patients were affected by rheumatism and were successfully helped by RhePort.de.

Further medical and statistical evaluation is still ongoing until end of 2016. The questionnaire has been updated in order to clarify misunderstandings from the patients' side. In the second phase of the evaluation an A-B study is conducted with patients who entered from RhePort.de compared to patients who started treatment by medical referral, which is common in Germany. Furthermore, male and female patients from various age segments and different regions are compared. The main question is, whether RhePort.de can successfully reduce the time between the first patient complaint and the diagnosis through a physician. Studies prove that the patients' quality of life increases inversely proportional to this period of time (Mau 2004). Nevertheless, it is apparent that the approach of using an integrative healthcare service platform like RhePort.de is a great chance to enhance rheumatology care in the 21th century.

For the future it is planned to increase the area of coverage and also add new value added services, like automated letters of physicians in order to co-found the network. Focus points for the future are: Scalability - enlarge stakeholder groups (e. g. health insurance funds, more physicians or pharma studies, etc.), Connectivity - add new functionality for smart devices (e. g. automated letters of physicians, apps to document pain of patients like rheumabuddy.com, integration of activity and movement trackers, etc.), Interoperability - use and license the platform to other medical disciplines (e. g. urology) in order to enhance a business model for RhePort.de.

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