

# A Patient Centered Infrastructure

Christian Seebode

**Abstract**—The Patient Centered Information Infrastructure supports information, communication and education in order to improve the level of health literacy of patients. Patients that understand their health situation are able to participate in healthcare delivery and improve their health outcomes. The Patient Centered Infrastructure is a collection of federated services which resides on top on a common information model for patients and supports the patient centered process. The Patient Centered process represents a cycle of steps that patients perform in order to participate in healthcare delivery and to take control of their personal health situation.

**Index Terms**— Patient Centered IT, Healthcare IT, Infrastructure, Knowledge Management

## I. INTRODUCTION

In order to give patients a possibility to participate more in healthcare delivery and to take responsibility for their action patients need access to information, communication and educational services. We present a Patient Centered Infrastructure which supports a patient centered process which represents an information cycle where patients improve their health literacy in an iterative way.

Health literacy has proven relationship with health outcomes and well-being of patients [1]. Many therapeutic interventions are not effective because patients do not understand [2] their situation or just forget to take the prescribed medication. Simple reminders are effective tools to support adherence.

Patient participation and the health literacy seem to be influenced by the quality of information accessible to patient. Patients have to become consumer, mostly consumer of health information but also of health services which they really understand. While participating and learning patients become also a source of health information. Patients and their knowledge are the most undervalued resource in healthcare delivery. This means that patients have to adopt a new role model too. Patients learn to demand and consume health information and improve their situation to achieve better outcomes. The main condition for active participation is open and transparent communication.

The Patient Centered Information Infrastructure supports information, communication and education in order to improve the level of health literacy in patients such that they may understand and consciously decide what is best for them. The Patient Centered Infrastructure is a collection of federated services which resides on top on a common information model for patients and supports the patient centered process.

The Patient Centered process represents a cycle of steps that patients perform in order to participate in healthcare delivery and to take control of their personal health situation and consists of the following steps:

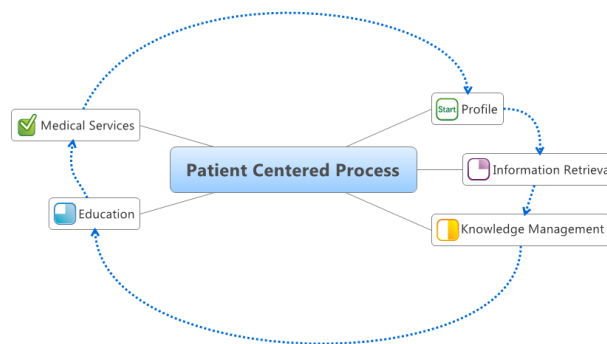


Fig. 1. The Patient Centered Process

- A. 1. *Store (Health Record Management)*
- B. 2. *Retrieve (Information Retrieval)*
- C. 3. *Gain Insight (Knowledge Management)*
- D. 4. *Learn (Education)*
- E. 5. *Act (Medical Services)*

## II. THE PATIENT CENTERED PROCESS

### A. *Store (Health Record Management)*

Patients assemble a personal profile with contains a personal health record and a knowledge base. This may contain input from other systems, the patient himself or a result from a previous cycle. The personal health record doesn't store only the data but also their semantics. This semantic health record consists of all the facts that have been collected through various procedure in healthcare delivery or represent dialogs or interactions that have been tracked by the system. Additionally patients administer

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Dr. Christian Seebode is CTO of ORTEC medical, Am Sandwerder 37, 14109 Berlin, Germany (e-mail: seebode@bfg-berlin.de)

reminders or schedules in a calendar.

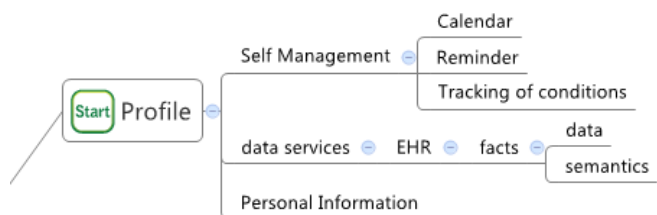


Fig. 2. Profile Services

**B. Retrieve (Information Retrieval)**

Patients seek health related information on the internet [3] but this should be related on the information and knowledge they possess (e.g. their level of health literacy). Sources of information may be Web, Case Databases, Literature or the information from EPRs or HIS. Even associated clinical text may be sources of information by means of linguistic analysis and text mining. Patients may use guided searches where the search reflects the meaning of search terms and phrases according to the underlying ontology. The guide may be any other participant (expert, patient, community or physician) which helps the patient to understand the result of the query. Alternatively patients may search information by querying a (semantic) search index that has been created by using the underlying ontology or does faceted browsing.

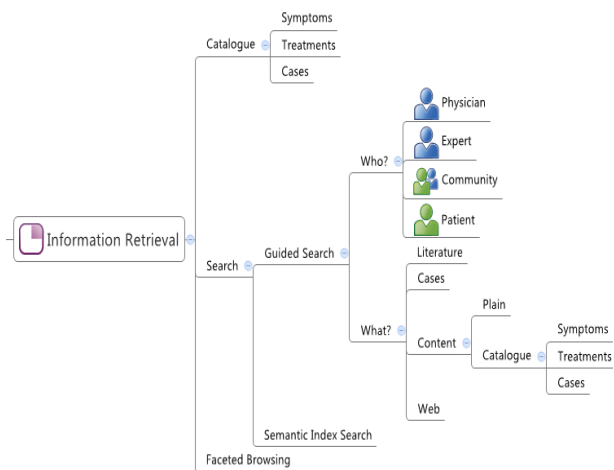


Fig. 3. Information Retrieval Services

**C. Gain Insight (Knowledge Management)**

Knowledge management is supported by formal representations of knowledge e.g. ontologies. Ontologies represent domain knowledge and are defined by experts or Patients who contribute their own knowledge base and align it with expert ontologies. Patients are able to build their own ontologies and annotate documents and search results with their own concepts and Links to the Linked Open Data Cloud by using a semantic workbench. Alternatively patients are able to use expert concepts or align their own with expert ontologies. Ontologies and

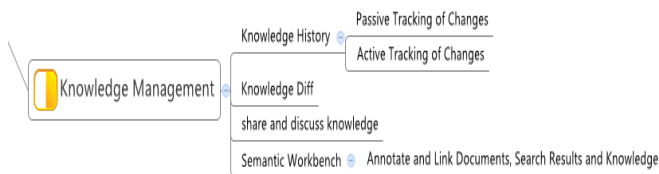


Fig. 4. Knowledge Management Services

corresponding facts are version-controlled such that diffs reflect the learning curve of the patient.

**D. Learn (Education)**

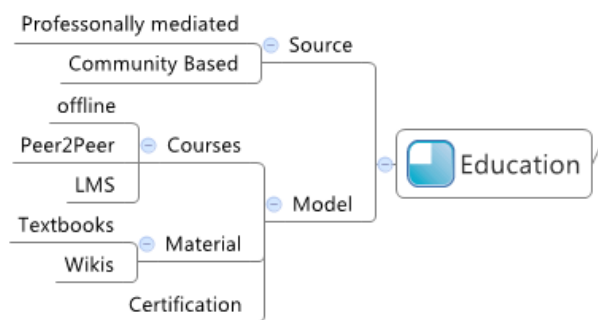


Fig. 5. Educational Services

Patients learn and build knowledge from the information they retrieved. Patients are educated by learning from information or from others. Patients are able to share this knowledge with other participant (expert, patient, community or physician) because of the common information model. Learning curves are represented by comparing different versions of the knowledge base. By providing transparent access to the patients knowledge base other participants are able to assess the level of knowledge and health literacy of the individual patient.

**E. Act (Medical Services)**

Patients use medical services and participate according to their level of health literacy. Medical services are offered offline or online. Medical services based on the information management capabilities of the Patient Centered Infrastructure are better understood by patients and support patient participation in healthcare procedures. Patients get decision support by consuming second opinion services or from the specific patient community that is associated with a service. Patients may document their personal level of health literacy by giving fine grained access to their

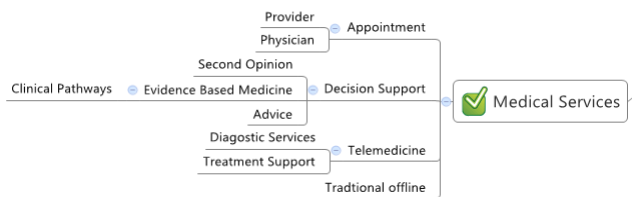


Fig. 6. Medical Services

personal knowledge base in order to receive personalized support.

### III. CONCLUSION

With a Patient Centered Infrastructure that is based on a semantic information model patients are able to manage their health information and knowledge. Information becomes an essential component of healthcare delivery that contribute directly to the health and wealth of the patient. In consequence the value of information has to be assessed and the quality of information has to assured. This will have an impact of how healthcare delivery is organized with empowered patients maybe mostly for those with chronic conditions [4]. Chronic conditions consume a great share of of the money spent in healthcare. An effective way to manage patient-centered information for patients with chronic conditions could influence the cost of healthcare delivery [5][6]. Patient controls directly part of the costs of healthcare delivery and indirectly via collaboration and participation in procedures. This is an important step towards accountable care where patients participate in healthcare delivery.

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