

Chapter 19

A View of Health Information Exchange: Towards a Digital Health Community

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ABSTRACT

The healthcare system in many countries is undergoing change, with the most important drivers behind this being: to improve the quality of the healthcare system, reduce the increase in costs and cope with a shortage of professional staff. These trends are influenced by the increase of chronic diseases across all ages and the aging society, due to longer life expectation. Trends within the changing healthcare system, the concept of a care cycle and the need for Health Information Exchange (HIE) are presented in the introduction. The role that HIE can play and the potential benefits for the stakeholders involved are presented, as well as some possible approaches to HIE and a description of the functionality of important components like electronic health record systems and personal health record systems. For optimal support to care givers and patients, access to data alone is not sufficient, but should be supplemented with advanced applications that can advise care professionals, support their working procedures and processes and support collaboration within multi-disciplinary care teams. The importance of interoperability is shown and followed by a vision of the future “Digital Health Community”, with two examples that are presented in detail, one from a patient’s point of view, the other from a care giver’s. The analysis section shows a list of potential building blocks which can be part of such a “Digital Health Community”.

INTRODUCTION

For more than a decade now the potential role of Information Technology within the context of changes in healthcare systems has been discussed

and some progress has also been made. Some important trends with respect to these changes in healthcare systems are shown in Figure 1, “*Trends in healthcare*”. The top-level drivers behind these trends are: to improve the quality of the healthcare system, reduce the increase in costs and cope with a shortage of professional staff. These trends are

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Figure 1. Trends in healthcare

- *From a single disease and treatment oriented approach to a full **care cycle** (covering prevention, early diagnosis, treatment, rehabilitation and managing chronic diseases) based approach evolving in due course to cover multiple diseases*
- *From a fragmented and solo approach to an **integrated** (multi-disciplinary, trans-mural), **team-based** approach to supporting new care models*
- *From an anecdotal and personal experience practice to an **evidence-based** practice using collective experience and proven protocols*
- *From a doctor and disease driven approach to a **patient-centric** way of working, taking the whole patient into account throughout his or her life (from cradle to grave)*

influenced by the increase in chronic diseases across all ages and the aging society, due to longer life expectation.

Healthcare institutes working at the front line of the changes in the healthcare domain are starting to adopt an approach called the ‘care cycle approach’, as defined in the book “*Redefining Healthcare*” (Porter, 2006). The author states: “Care Cycles are the best way to transform Healthcare from a zero-sum game to a patient-value driven industry”. Related to the use of information technology in healthcare delivery, the following is mentioned:

- The information should be collected and stored around the patient. All information should be tied to the individual throughout his life.
- Electronic patient records, including images and lab results, are essential: they allow for better integration across care givers and different care locations.
- Organizational improvements can only succeed when clinical, administrative and financial information is brought together,

otherwise optimization to achieve patient value is not possible.

- All data should be sharable, and seamless integration of systems is needed. This puts a high emphasis on interoperability, data standards and security standards.
- The aggregation of information should be based on the medical condition and the process definitions should be based on the specific medical condition so as to give optimal support to care givers.
- Stepwise implementation is important in order to build up confidence by the users. However, the steps should be carefully planned and dependencies between successive steps should be identified and taken into account.

With respect to care cycles one should be aware that during a person’s life a care cycle relates to the evolution of a disease within a patient and in the case of chronic diseases might contain cycles in treatment. The essence is that the complete care process is focused on the patient and his or

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