Building an infrastructure to improve cardiac rehabilitation: from guidelines to audit and feedback
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INTRODUCTION TO THE RESEARCH TOPICS AND CONTEXT

Building an infrastructure
The imperative for health systems to deliver better care, for more people and from fewer resources, is stronger than ever. There is a growing demand for care services, fuelled by the needs of ageing populations with an increasing prevalence of chronic diseases, the growth in healthcare technologies and historical high investments in health care services [1]. Therefore, the healthcare sector vigorously seeks opportunities to learn on, and apply what is best in practice. However, a variety of factors result into suboptimal learning of health systems: health data reuse is currently limited and delayed, and information management is too costly [2]. Some of these factors are socio-cultural: e.g. system complexity, parties determined to protect their vested interests or established professional norms around evidence-based practice. Other factors relate to availability and accessibility of data required to generate knowledge for guiding best decisions. This data is either unavailable, incomplete, outdated, inaccessible, not translated into meaningful information or just not used in daily practice by the decision makers. All these factors impede the learning of health systems. For example, it takes 17 years on average before validated clinical knowledge finds its way into routine clinical practice [3]. Improving the capability to share and reuse data generated in health systems—and harness its potential to generate knowledge rapidly and inform healthcare practice, research, political and individual patients’ decisions—is expected to induce considerable transformations [4, 5].

Within other sectors, individual organisations and collaborating groups have already created the necessary infrastructures to leverage their data for increased productivity, gain competitive advantage, and revolutionize business models. Attempts to employ these types of approaches to realise transformative impacts for one of the most challenging societal problems—improving health—did not result in similar success. The health sector can point to current examples of large clinical research networks, as well as increasing adoption of electronic patient record (EPR) systems and other information technologies. Yet this sector has not undergone the type of IT-enabled transformation, visible across other industries, to create an infrastructure supporting intensive data sharing and learning [6].

One widely conceived concept for realising necessary transformations, at significant scale and scope in the health domain, is generally known as the ‘Learning Health System’ (LHS) [7]. The LHS is defined as a vision for an integrated health system in which progress in science, informatics, and care culture align to generate new knowledge as an ongoing, natural by-product of the care experience. The goal is to seamlessly refine and deliver best practices for continuous improvement in health and healthcare [8]. Though articulated in various forms, the underlying concept is straightforward: harness the power of data and analytics to learn from every patient, and feed the “what works best” knowledge back to clinicians and all other stakeholders to create learning cycles of continuous improvement (see Figure 1).

Achieving a LHS requires exploration of methods to connect the multiple stakeholders and fragmented repositories of data and knowledge in the complex health ecosystem in one
infrastructure; enabling them to align with, and learn from each other over time [4]. This thesis explores on how we can use the LHS principles to realise such an infrastructure to connect physicians, other health professionals, managers, professional associations, EPR developers, patients and researchers in the field of cardiac rehabilitation (CR) in the Netherlands. The results may contribute in improving the field of CR care in general, increasing knowledge on facilitators of continuous learning and improvement, and identifying success factors for building an LHS infrastructure which can be used in CR and other domains of health care.

To improve
Health systems—at any level of scale—can become learning systems when they continuously and routinely, study and improve themselves by performing so called ‘Virtuous learning cycles’ [4]. Within the context of systematic quality improvement these cycles are also known as Plan-Do-Study-Act (PDSA) cycles, constituting a component of the Model for Improvement [9]. Basic principles of these two cycles are comparable. After a decision is made to study a problem of interest, data should be collected (step 1), assembled (step 2) and analysed (step 3), followed by interpretation of results (step 4) in order to lead to tailored messages (step 5), and followed by actual improvement actions (step 6). To evaluate changed practice and guarantee constant improvement over time, the learning cycle should have a continuous character.

In a large scale health system multiple stakeholders, like biomedical researchers, health care delivery parties, the government, and patient groups, all formulate their own problems of interest, resulting in multiple learning cycles. Without a supportive, integrated platform every cycle requires its own agreements, technology, staffing, analytics and dissemination mechanisms. In contrast, the LHS infrastructure supports multiple simultaneous learning cycles at the same time with one platform that empowers multiple and diverse stakeholders to individually and collectively drive innovation across the healthcare ecosystem. This platform provides data as a service to facilitate and intensify data sharing and (re)use. Such as, the LHS can underpin a host of unforeseeable innovations in data-, knowledge-, and evidence-driven health-care, bio-surveillance in the public interest, and health-related research and development [4]. In other words: “If you want to get 350,000 people per day across a river, do you build 350,000 rowboats? No, you build a bridge!“ (Charles Friedman [10]).
Despite major improvements in diagnostics and interventional therapies, facing (multiple) chronic diseases remains a major health care and socio-economic burden. This burden increases and is closely correlated to economic growth and an ageing population [11]. Health behaviour change is a key component for chronic disease prevention. Studies have shown that 90% of type 2 diabetes, 80% of coronary heart disease (CHD), and 70% of all strokes are potentially preventable by a healthy lifestyle, including non-smoking, maintenance of a healthy bodyweight, regular physical activity, healthy eating habits, and moderate alcohol consumption [12]. Whereas treatment of traditional risk factors such as hypertension and dyslipidaemia is improving, inactivity and obesity are increasingly important determinants of cardiovascular mortality in The Netherlands [13]. Cardiovascular diseases, such as CHD, is the main cause of death in Europe, with around 4.1 million deaths per year [14] and they are accountable for 28% of the total number of deaths in the Netherlands [13]. Health authorities, care providers and the general population have started to recognize that the fight against chronic diseases like CHD, can only be won by lifestyle changes and prevention. As such, increasing investments in interventions for lifestyle changes and prevention are required [15]. Likewise, there is an overwhelming evidence on the efficacy of secondary prevention initiatives, including cardiac rehabilitation (CR), in terms of reduction in morbidity and mortality [16, 17].

Outpatient CR programs offer a cost-effective, multidisciplinary, comprehensive approach to address CHD risk factors and to support patient in restoring their optimal physical and psychosocial condition [15, 18]. CR is widely recommended for all CHD patients who have been hospitalized for an acute coronary syndrome (ACS) and for those who have undergone coronary revascularization (coronary artery bypass graft surgery [CABG] or percutaneous
coronary interventions [PCI]) or valvular surgery [15, 19]. Studies show that CR is also beneficial for patients with other chronic cardiovascular conditions such as stable angina pectoris (AP) and chronic heart failure (CHF) and for subjects with a high risk for developing cardiovascular disease [20]. CR teams usually include cardiologists, nurses, physical therapists, psychologists, dieticians, social workers, and rehabilitation physicians. The program starts with an extensive needs assessment procedure where data items concerning the patient's medical, physical, psychological, and social condition and lifestyle are gathered [15, 21]. Based on the results and the patients' preferences, an individualized rehabilitation programme is offered. This consists of multiple rehabilitation goals (e.g. 'Optimize exercise capacity' or 'Regain emotional balance') and usually up to four possible therapies: exercise training, education and counselling, lifestyle modification, and relaxation and stress management training and, if needed, several forms of individual therapy (e.g. by psychologists, social workers or dieticians) [15, 21].

In a recent Dutch population based cohort study carried out by our research group, it was shown that CR was associated with a 35% reduction in mortality over a follow-up period up to four years [22]. This effect of CR in the community is consistent with previous, comparable studies in the United States [23] and Canada [24]. Despite the known benefits of CR, and despite the widespread endorsement of its use [15, 25], CR services are yet often under-utilized, poorly standardized, and do not follow the available scientific evidence [26].

From guidelines
Clinical practice guidelines sum up available scientific evidence and/ or expert opinions in systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances [27]. They may offer concise instructions on which diagnostic or screening tests to order, how to provide medical or surgical services, duration of hospital stay of patients, or other details of clinical practice. Guidelines are considered essential instruments to improve the quality of care as their potential benefits are reduced practice variation, reduced costs and improved patient outcomes. [28]. Despite their wide promulgation, professionals' (like in the field of CR) often face multiple barriers to actually follow guideline recommendations.

A frequently used classification for barriers to guideline implementation is a division into individual (‘internal’) and environmental (‘external’) barriers [29]. Internal barriers concern professional's knowledge of, and attitude towards guidelines. To improve these, computerized decision support (CDS) is known to be effective since it can provide guideline-based recommendations at the time and place where clinical decisions are made [30]. However, medicine is largely practiced by teams of healthcare professionals embedded within complex organisations. These professionals may also encounter external barriers hampering their ability to execute guidelines. These barriers stem from environmental factors related to the team, organisation or health system they work in; e.g. lack of resources, staffing shortages or maintenance and equipment problems.
An EPR system with computerized decision support (CDS) functionalities was previously developed in the Netherlands, to improve concordance with CR guideline recommendations for the patient tailored CR program [31]. Although the CDS has proven itself to be effective [32], the system has not improved concordance with all guidelines’ recommendations (e.g. uptake for the lifestyle change therapy), and both undertreatment of patients concerning the relaxation therapy, as well as considerable practice variation in concordance with guideline recommendations remained for all four therapies. Following insights from the literature on the different types of barriers to guidelines implementation, an intervention strategy with supplementary components directed at both internal and external barriers [29] might create the necessary conditions and resources for further improving CR guideline concordance. More research is therefore required to understand how CDS improved concordance with some of the CR guidelines and which additional strategies for change need to be considered to overcome the remaining barriers.

To audit and feedback

In other fields of health care, audit and feedback (A&F) on health care performance and outcomes have been shown to be an effective quality improvement method to overcome external barriers and improve professional performance [33]. In a setting where CDS is already used to provide patient-tailored advice in daily care at the individual professional level, A&F can be used in addition to extend behind the level of the individual professional and inform decisions on the medical team and organisational level [34]. A&F consists of providing health care professionals with an objective summary of their clinical performance over a specified period of time [33]. Clinical performance is typically measured by a set of performance indicators derived from clinical guidelines or expert opinion, each representing a certain quality aspect of care (e.g. patients receiving a treatment according to guideline recommendations, mortality rates or successful smoking cessation). Characteristics that may enhance the effect of indicator-based performance feedback are a combined with educational outreach visits, providing feedback multiple times, and involving the entire team in action-planning and goal-setting activities [33].

The LHS concept envisions that, in order to be successful, the learning system must be constructed to function bi-directionally [8]; meaning that it must have both an “afferent” mode of operation to assemble data for analysis (left part of the learning cycle in Figure 1) in addition to an “efferent” mode for disseminating the knowledge that results from the analysis back to the parties that provided the data (right part of the learning in Figure 1). This supports that, in a setting where an EPR with CDS is already used at the point of care (afferent mode), this intervention can be well combined with an A&F intervention (efferent mode). In that case automatically collected EPR data can serve as input for learning cycles with tailored messages to support improvement actions in daily practice. The feedback of the CDS system at the individual level is completed with feedback from the A&F intervention at the team and organisational level. Such an approach may support health care organisations to continuously and routinely, study and improve themselves.
AIMS OF THE THESIS

The overall aim of this thesis is to build an infrastructure, based on the LHS principles, to continuously improve professional performance in the field of CR. The infrastructure will integrate both technical and organisational components. The technical components should allow the co-use of data collected in the EPR with CDS, to realise an A&F system. The organisational components will concern the active involvement of all stakeholders to receive their necessary input and commitment for the optimal functioning of the technical infrastructure, and support services for multidisciplinary CR teams during outreach visits to actually use the A&F system and improve their performance by executing the LHS learning cycle. The thesis describes the learning process, the results of this approach, and the challenges involved. The work in this thesis elaborates on both previous research in the field of CR in the Netherlands as well as on previous studies on successful characteristics of interventions to improve health care, described in the literature. To achieve our goal, we addressed the following research aims:

1) To assess current improvement challenges in the field of CR
2) To develop an infrastructure to facilitate continuous improvement
3) To assess the effect of a web-based A&F system with outreach visits on professional performance

OUTLINE

Part I consists of chapter 2, 3 and 4 and focuses on assessing current improvement challenges in the field of CR. Chapter 2 describes the results of a qualitative study in the field of CR after the implementation of a computerized CDS system. Although the CDS system was effective in improving concordance with the guidelines recommendations, barriers for further improvement due to constraints within teams and organisations, and related to practicability of the underlying guidelines, remained. To address those barriers, Chapter 3 describes the process of embedding two learning cycles, starting with data collection from a computerized CDS system, in a continuous improvement strategy. This strategy combines the CDS system with a benchmark-feedback cycle and periodic updates of the underlying guidelines. As such, our strategy addresses not only the decision-making process of individual professionals but also decisions made at higher levels of clinical organisations in two knowledge-management cycles. Chapter 4 outlines a study that assessed CR uptake rates and identifies factors that determine uptake in a large insurance claim database in the Netherlands. As a previous European survey study estimated that fewer than half of eligible cardiovascular patients in Europe are referred to CR, our large population based cohort study assessed exact CR uptake rates using systematically recorded health insurance data.

Part II consists of chapter 5, 6, 7 and 8 and focuses on the development and improvement of the multiple components of the LHS infrastructure to connect the stakeholders and fragmented repositories of data and knowledge in the field of CR. Chapter 5 describes a mixed method
usability approach which we used to assess and improve the usability of the user interface of the CR EPR. The EPR is used by CR professionals to determine a patient-tailored rehabilitation program at the start of the rehabilitation. The recommendations for redesign for the study were implemented by the developers. Chapter 6 describes how we, together with representatives of all professional CR associations, revised the Dutch clinical algorithm for assessing patient needs at the start of the rehabilitation. This revision was based on identified problems CR professionals faced in daily practice. Chapter 7 presents a modified Rand method which we used to derive a set of quality indicators for CR. This method combines results from a literature search and guideline review with the knowledge of an expert and patient panel in an extensive rating and consensus procedure. Chapter 8 describes the development and first experiences of CARDSS Online; a web-based A&F system to facilitate continuous improvement by multidisciplinary care teams. The system is based on the principles of the continuous learning cycles to actively involve the teams in using indicator-based feedback to improve their clinical performance.

Part III consists of chapter 9, 10, 11 and 12. These chapters discuss the design and results of our randomized clinical trial (RCT) with the web-based A&F intervention combined with outreach visits. In Chapter 9 we describe the rationale and study protocol to evaluate the effect of the system in the field of CR where an existing CDS is already used to guide professionals’ decisions. We describe two outcome measures: guideline concordance and professional performance. Chapter 10 shows the preliminary result of the intervention on solely on the concordance with guideline recommendations. Chapter 11 shows the final results on both clinical performance measured by a set of quality indicators (care processes and patient outcomes) and guideline concordance. Chapter 12 describes the results of a study in which we used a structured qualitative approach, concept mapping, to assess experiences by CR teams who participated in the RCT. This method provided insight on organisational and workflow factors needed to successfully implement the web-based A&F intervention with outreach visits to improve the quality of CR care in the Netherlands.

Finally a summary and general discussion of all findings in this thesis is presented in Chapter 13. This chapter summarizes the results of all previous chapters, discusses them in the wider context of the LHS principles and elaborates on ideas for future research.
REFERENCES


