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Faculty of Health Sciences Univestity of Southern Denmark

Cecilie Lindström Egholm

Implementation of national clinical guidelines and clinical quality registries to improve cardiac rehabilitation

November 2018

Faculty of Health Sciences, University of Southern Denmark

Author:

Cecilie Lindström Egholm Correspondence: cecilie.lindstrom.egholm@rsyd.dk

Supervisors:

Main supervisor:

Ann-Dorthe Olsen Zwisler, REHPA: The Danish Knowledge Centre for Rehabilitation and Palliative Care, University of Southern Denmark and Odense University Hospital, Denmark

Co-supervisors:

Per Nilsen, Division of Community Medicine, Department of Medical and Health Sciences, Linköping University, Sweden Gitte Bunkenborg, Department of Anesthesiology, Holbaek University Hospital, Region Zealand, Denmark

Opponents:

Hanne Kaae Kristensen (*chair*), Dept. of Clinical Research, Rehabilitation, University of Southern Denmark, Odense, Denmark Knut Borch-Johnsen, Holbæk University Hospital, Holbæk, Denmark Liselotte Schäfer-Elinder, Dept. of Public Health Sciences, Karolinska Institutet, Stockholm, Sweden

Defence:

May 3rd 2019, at 15.00 pm, in the Auditorium, Holbæk University Hospital, Holbæk

The project was funded by:

The Unit for Production, Research and Innovation, Region Zealand; REHPA - The Danish Knowledge Centre for Rehabilitation and Palliative, University of Southern Denmark and Odense University Hospital; the Department of Medicine, Holbæk University Hospital; and the Region Zealand Health Scientific Research Foundation.

Contents

Papers included in this Thesis	6
Abbreviations	7
Resumé (Danish Summary)	8
English Summary	10
Preface	12
Introduction	16
Background	18
Evidence-based Practice and Implementation Science	18
Cardiac Rehabilitation	23
Danish National Initiatives to Implement Cardiac Rehabilitation Services	27
Study Rationale	32
Aim and Objectives	
Design and Methods	34
Design	34
The Case Study Approach	35
Methods – Quantitative Studies	41
Methods – Qualitative Study	44
Ethical Considerations	47
Results and Findings	49
Paper I: Mapping of CR Services in Hospitals and Municipalities	49
Paper II: Barriers and Facilitators for Registry Implementation	51
Paper III: Using Data from the Danish Cardiac Rehabilitation Database	53
Discussion	55
Discussion Part 1: Closing Evidence-Practice Gaps with the Guideline?	55
Discussion Part 2: What does it Take to Implement a CR Registry?	58
Implications for Practice	65
Methodological Considerations	67
Conclusions	73
Further Research	74
References	75

List of Appendices

Appendix I:	DHRD indicators
Appendix II:	NACR minimum standards
Appendix III:	DHRD structural survey questionnaire – nurses, hospital 2013 section
Appendix IV:	Quality improvement While Adopting Quality registry outcomes survey (QWAQ) – Danish version for DHRD
Appendix V:	Invitation letter – English version

Papers included in this Thesis

This thesis is based on the following three original papers, referred to in the text by their Roman numbers (I-III):

- Implementation of a politically initiated national clinical guideline for cardiac rehabilitation in hospitals and municipalities in Denmark. Health Policy 2018;122:1043-51. (Paper I)
- "Struggling with practices" A qualitative study of factors influencing the implementation of clinical quality registries for cardiac rehabilitation in England and Denmark. (in review) (Paper II)
- Facilitators for using data from a quality registry in local quality improvement work a survey study of cardiac rehabilitation. (submitted) (Paper III)

Abbreviations

BACPR	British Association for Cardiovascular Prevention and Rehabilitation
CR	Cardiac Rehabilitation
CFIR	Consolidated Framework for Implementation Research
DHRD	The Danish Cardiac Rehabilitation Database
NACR	The National Audit for Cardiac Rehabilitation (UK)
QWAQ	Quality improvement While Adopting Quality registry outcomes survey

Resumé (Danish Summary)

Formålet med denne afhandling var at øge vor forståelse af implementering af nationale kliniske retningslinjer og nationale kliniske databaser for at forbedre hjerterehabilitering.

Dette formål stammede fra en erkendelse af de udfordringer med implementering som findes i sundhedsvæsenet generelt, hvor hjerterehabilitering er en case som illustrerer udfordringerne med at anvende evidensbaserede anbefalinger i praksis, hvilket resulterer i en kløft mellem viden og praksis. Danske myndigheder har, som en respons på suboptimal indhold og kvalitet af hjerterehabilitering i Danmark, lanceret to strategier for at forbedre tilbuddet: en national klinisk retningslinje og en national klinisk kvalitetsdatabase. Disse initiativer har til formål at føre til ændringer inden for praksis, men de kan være udfordrende at implementere. Med afsæt i disse forhold var målet for denne afhandling at studere implementeringen af de to strategier, hvilket blev gennemført i tre forskellige studier og ved brug af både kvantitative og kvalitative metoder.

Målet med det første studie var at vurdere udfaldet af implementeringen af den nationale retningslinje, ved at fastlægge i hvilken udstrækning danske hjerterehabiliteringstilbud følger de nationale anbefalinger. Vi gennemførte en spørgeskemaundersøgelse lige før lanceringen af den nye retningslinje og med en opfølgning to år senere, med spørgsmål til indhold og kvalitet af indsatser. Både hospitaler og kommuner deltog i undersøgelsen, da de deler ansvaret for hjerterehabilitering i Danmark. Resultaterne viste, at der ikke var nogle forbedringer i kommunerne i den pågældende periode, medens nogle forbedringer blev rapporteret på sygehusniveau. Der var betragtelig variation i hjerterehabiliteringstilbuddene, og overordnet set var der plads til forbedring.

Det andet studie satte fokus på implementering af kvalitetsdatabasen, herunder især dataindsamling og dataindtastning. Vi gennemførte interviews med klinisk og administrativt personale, der var involverede i disse opgaver, for at afdække hvordan de oplevede implementeringsprocessen. Ud over det danske register var yderligere en database, den Britiske, inkluderet i dette studie, for at give et bredere perspektiv og mulighed for øget forståelse for hvordan personale oplever det at arbejde med hjerterehabiliteringsregistre. Ved hjælp af indholdsanalyse fandt vi både ligheder og forskelle mellem de to registre. Generelt havde implementeringen kun fået begrænset opmærksomhed. Personalet oplevede en mangel på støtte

fra ledelsen og mange fandt det udfordrende at få brugen af registret indpasset i en travl og kompleks dagligdag.

Målet med det tredje studie var at måle i hvilken grad feedback-data fra den danske database bliver brugt i forbindelse med lokalt kvalitetsudviklingsarbejde, samt hvad der understøtter sådan brug af data. Et svensk spørgeskema omhandlende brug af database-data blev oversat til dansk og sendt til både klinisk personale og ledere i alle hospitalsafdelinger, som bidrager med data til det danske register. Resultaterne indikerede en begrænset brug af data, dog var der forskel mellem ledernes og personalets opfattelser af databrug. Blandt de understøttende faktorer for at bruge data var høj datakvalitet og brugbarhed, at ledelsen var involveret, samt personlig motivation.

Overordnet set peger denne afhandling på, at implementeringen af både retningslinjen og databasen for hjerterehabilitering har fået sparsom opmærksomhed. Når implementering ikke er vel gennemført kan sundhedsvæsenet ikke forvente at kunne høste udbyttet fra at have lanceret disse strategier.

English Summary

The aim of this thesis was to improve our understanding of implementation of national clinical guidelines and national clinical registries to improve cardiac rehabilitation (CR).

This aim originated from an acknowledgement of the challenges of implementing new research based knowledge in healthcare in general and CR is a case that clearly illustrates the difficulties of moving recommendations into evidence-based practice, resulting in knowing-doing gaps. In response to the insufficient provision and quality of CR in Denmark, Danish authorities have launched two strategies to improve services: a national clinical guideline and a national clinical quality registry. While intended to improve the implementation of CR, these strategies may, however, in themselves be difficult to implement. Hence, this health services research PhD project investigated the implementation of these strategies in three studies, using both quantitative and qualitative methods.

The objective of the first study was to assess the service level outcomes of guideline implementation by determining the extent to which Danish CR services adhere to national recommendations. By means of a follow-up questionnaire survey, we studied the content and quality of services according to guideline-based recommendations immediately before launch of the new national clinical guideline and two years later. The study included both hospitals and municipalities, as these two settings share responsibility for the provision of CR in Denmark. We found considerable variation in CR services between units and, overall, we found there was room for improvement. No changes were found in the CR services offered at the municipality level, following the launch of the guideline, while some improvements were reported at the hospital level.

The second study focused on registry implementation, in particular the processes of data collection and data entry. Interviews were conducted amongst staff involved in both these tasks, in order to explore how they experienced the process of registry implementation. To broaden perspectives, two registries were included: the Danish Cardiac Rehabilitation Database and the British National Audit of Cardiac Rehabilitation. Content analysis identified both similarities and differences within and between the studied registries. In general, implementation received little focused planning at a department level. Staff experienced a lack of active support from

management, and seemed to experience challenges in fitting registry use into their busy and complex daily practice.

The objective of the third study was to measure the extent of registry feedback used in local quality implementation work and to identify the factors facilitating such use of data. A questionnaire regarding perceptions of the registry and departmental use of registry data was sent to frontline staff and managers in all hospital departments taking part in the Danish CR registry. Results suggested a relatively low use of data, although managers and frontline staffs' perceptions of use of data differed. Factors that facilitated data use were identified to include perceived quality of high level and usefulness of data, involvement of managers and personal motivation.

Overall, the thesis suggests that implementation of the CR guideline and registry, in general, was relatively modest. Without a thorough implementation, healthcare cannot expect to harvest the benefits from launching these strategies.

Preface

The research described in this thesis was conducted between December 2015 and November 2018, although with initial data collection in 2013. The work was made possible by a cooperation between the Unit for Production, Research and Innovation, Region Zealand, the Danish Knowledge Centre for Rehabilitation and Palliative Care, University of Southern Denmark and Odense University Hospital, and the Department of Medicine, Holbæk University Hospital. The work is centred on the field of implementing evidence-based practice to improve the quality of cardiac rehabilitation.

There have been many instances in my working life where I have reflected upon whether we actually implement new knowledge based on evidence in healthcare and, thereby, use resources in a sensible way. The following two occasions, encountered in my daily working life, have had a particular influence on why I came to pay particular interest to this field. The first was when I, as a young student assistant at the Danish Health Authority, took part in the celebration of the release of a new health technology assessment report. My more experienced colleague sighed and commented that although the report held important conclusions, not long from now it would probably be collecting dust on a shelf. I wondered: "Then for what use?" The second occasion occurred when I was working as an administrator for a nationwide clinical quality registry. One particular hospital department continued to enter a very low amount of data into the registry, despite conducting several training sessions for staff. The Head of the Registry Steering Committee presented what I thought at the time to be a very withdrawn approach to the matter: "It's the chief physician, he doesn't want to participate. We'll just have to wait until he retires." I still do not know whether that turned out to be a successful strategy. However, this remained at the back of my mind.

I continued my career as a consultant within research administration and my manager at the time happened to be preoccupied with the gap between research and practice, also known as the evidence-practice gap or the knowing-doing gap. He strongly encouraged me (I owe you thanks for this, Steffen Groth) to venture into the field and undertake a PhD. One day, a very interesting case appeared in the form of an e-mail with news from the Danish Health Authority: A new national clinical quality registry for cardiac rehabilitation had been implemented. This immediately caught my attention. Implemented? I contacted the Head of the Steering

Committee, Ann-Dorthe Zwisler, and asked how this implementation had been accomplished. I was told that it had been launched to all stakeholders. Not what I would regard as implemented but, fortunately for me, she was open minded enough to welcome me to study the use of the registry for improving quality of cardiac rehabilitation (CR). That was the start of this PhD journey.

It has been said that it is vital to have a deep understanding of the field that one studies in implementation projects, in order to be able to explore the deeper reasons for success or failure. It has been both a challenge and a privilege for a non-clinician like myself to take a leap into the field of CR. Fortunately, I have had tremendous help from the staff at the Medical Department at Holbæk Hospital, where I have been employed during my work, from colleagues and supervisors with clinical backgrounds and by spending time with practitioners in the field. Through informal conversation and, actually, also just by being with them and paying attention to the little remarks and the small everyday issues, I have acquired invaluable pieces of knowledge which have contributed to my overall understanding of the field, including things that nobody thought of mentioning in the formal research interviews and I did not think of asking. Furthermore, I had the joy of spending five weeks at Deakin University in Australia and made several visits to the UK. In both countries, I had the pleasure to meet with researchers and practitioners working with CR, which has widened my international perspectives on the challenges of improving CR services through building and managing registries.

I owe my gratitude to many for helping me in the work with this thesis:

- Ann-Dorthe Zwisler, my main supervisor, thank you for letting me on board the DHRD, for your enthusiasm, good ideas, patience and enormous ability to be present and focused. Your ability to make things happen is an inspiration.
- Per Nilsen, co-supervisor, thank you for your insightful advice, focus on the detail, very encouraging and positive attitude and constant focus on learning and widening perspectives.
- Gitte Bunkenborg, co-supervisor, thank you for your devotion to this project, for your very good guidance and patience, methodological insights and, not least, for your warm support.
- Lotte Helmark, my partner in crime, thanks for hour and hours of hard work, your knowledge of practice, for inspiring company and for your Jamie Oliver gold card.

- Morten Hulvej Rod and Paul Bartels, who had roles as expert advisors in writing the PhD protocol and in the first study. Thanks for your contribution and insightful comments.
- Knud Rasmussen and the Unit for Production, Research and Innovation, Region Zealand, for believing in me and supporting my work.
- The Department of Medicine at Holbæk University Hospital, who have financially supported my work and welcomed me as employed in the department while conducting my PhD project.
- The entire CR team at Holbæk University Hospital. You have patiently put up with my questions and ideas and given me invaluable insight into everyday CR practice and into the struggles of putting the Danish Cardiac Rehabilitation Database into practice.
- Patrick Doherty, Nerina Onion, Corinna Petre, Alexander Harrison and Karen Cardy in the team administrating the National Audit for Cardiac Rehabilitation (NACR) at the University of York, for loads of interesting information and conversations about the British NACR-registry and invaluable help in the process of recruiting study participants and arranging study tours.
- Henriette Knold Rossau and Jan Christensen, at REHPA, for practical help and advice with the statistical analyses.
- Carina Bruun Henriksen, PFI, Maryam Pedersen, Tina Broby Mikkelsen, Sarah Egelund Frausing and Maiken Bay Ravn, at REHPA, for kindly helping me collect survey data.
- All my colleagues in Forskningens Hus, Holbæk for moral support, good laughs and interesting discussions about work and much more.
- Alison Hutchinson and Helen Rawson at the Centre for Quality and Patient Safety Research, Deakin University. You welcomed me warmly and were ever so helpful in introducing me to individuals who broadened my perspectives of CR and registries.
- Anne Nakano, Charlotte Cerqueira, Hanna Joensen and Camilla Plambeck Hansen at the RKKP. It has been a pleasure working with DHRD with you.
- Ann-Cathrine Eldh and Ulrika Winblad for kindly letting me use your questionnaire and for engaging in the translation and writing process.
- Rebecca Taylor for proofreading this thesis.

- A very special thanks to all the staff in both Denmark and England who have patiently responded to my questionnaires and participated in interviews. Your experience is what makes us all a little wiser.
- Last but definitely not least, my dear Troels, Clint and Aksel. You have been my safe haven in this process. Thank you for your patience, understanding and support.

Introduction

Implementation has become something of a buzzword in healthcare. It has been recognized that implementation of evidence does not happen by itself; we need to pay particular attention, in order to put evidence into practice. However, what also seems to become increasingly evident is that implementation is really difficult. In fact, it is so difficult that it has been argued that healthcare could gain more by becoming better at implementing what we already know, than by doing research to gain new clinical knowledge. Much has already been written and spoken about the challenges of implementation to improve quality of care. This thesis too focuses on these challenges and is carried out in the clinical area of cardiac rehabilitation (CR). So, why is this study important?

Simply because we are not there yet. CR is a clinical area in which, despite solid evidence being recommended through guidelines for the past decades, a vast gap still exists between evidence and clinical practice. This thesis focuses on the implementation of two strategies that have been launched by the Danish authorities in response to the insufficient quality and equity of CR: a national clinical guideline and a national clinical quality registry. These are both aimed at improving services in both the hospital and municipality sectors, as they share responsibility for CR.

The implementation of guidelines has already been extensively studied and their use in clinical practice has been found challenging, which made it an important starting point for this study seeking to map adherence to the guideline recommendations. This was especially interesting in municipalities, which have been the 'new kids on the block', only recently seriously getting into fulfilling their role in rehabilitation. Did practice change following the launch of the guideline? Knowledge of what kinds of gaps there are in which settings are central to both practitioners, decision makers and researchers alike, to know where to put in extra effort into helping services become more evidence-based. This knowledge is crucial if progress is going to be made.

The majority of effort in this thesis was put into studying the implementation of the clinical quality registry for CR. Many seem to have high expectations of registries as a quality improvement strategy and the number of registries is growing, but research still has not been able to show that registries, in general, have a clear, positive impact. In this thesis, I argue that

this could be due, at least in part, to poor implementation of the registries and therefore, I wanted to illustrate what may challenge the new CR registry's success.

Since the registry was to be applied in both hospital and municipalities, the original intent of this thesis was to study implementation in both of these sectors. However, due to legal and technical issues, the municipalities did not start using it and, instead, the British cardiac rehabilitation registry was included in the study as it offered an opportunity for gaining valuable insights beyond the Danish registry.

It is vital to make registry stakeholders, i.e. CR practitioners, managers, administrators and policymakers, aware of context specific factors that both help and hinder implementation. While all stakeholders are skilled experts in their respective fields, they may have less knowledge about quality improvement and implementation to facilitate a change in practice. It is my hope that this thesis will contribute to broadening their perspectives with an insight into the evidence relating to implementation. Such a knowledgebase could be a key factor in the pursuit to improve CR services across sectors. To the field of implementation research, this thesis aim to contribute empirical knowledge to close the evidence-practice gap in the literature currently available about implementation of CR registries and the routine use of these registries.

Background

This chapter gives an introduction to the concepts used in the thesis. It starts by briefly introducing evidence-based practice and implementation, followed by a description of the key concepts in implementation science: a scientific field that has emerged as a response to the challenges of implementation. Next, CR is described, illustrating a case where evidence has not been fully implemented into practice. The chapter concludes by presenting clinical guidelines and clinical registries, as these initiatives were launched to improve CR services in hospitals and municipalities in Denmark. While intended to improve clinical practice, they may in themselves be challenging to implement and use.

Evidence-based Practice and Implementation Science

There is a strong focus within healthcare that clinical practice should be evidence based rather than based merely on experience or intuition about what might work or be most effective. The concept of evidence-based practice stresses utilization of best available empirical evidence to lay the ground for decisions and actions within clinical practice, encompassing all kinds of interventions, such as prevention, diagnosing, treatment and rehabilitation [1]. This concept gained ground in the 1990s and was a reaction to a prior emphasis on more unsystematic knowledge sources, including intuition, clinical experience and pathophysiological explanations as sufficient grounds for clinical decision making [2]. It was recognized that there was a value in identifying what actually works, in order to promote the widespread use of such practice.

In the original sense of the concept, evidence-based practice is based on three sources of knowledge: the best available scientific evidence, clinical experience and the patients' values and preferences [3]. The notion is that by combining these sources of knowledge, healthcare professionals will be able to identify the most efficacious interventions and, hereby, achieve best possible quality of care [3]. Considering this original meaning, evidence-based practice is a demanding way of working, where the individual clinician is supposed to critically appraise the scientific literature him/herself, requiring both time and competencies [2]. To aid healthcare professionals in achieving evidence-based practice, research findings are often aggregated, assessed, condensed and communicated back to relevant stakeholders together with

recommendations for practice in the form of clinical guidelines or similar compilations of knowledge [2].

In the earliest days of the evidence-based practice movement, it was believed that the mere existence of knowledge based on systematic scientific research would lead to practice changes [4]. During the past two decades, however, this presumption has been challenged with growing recognition of the difficulties of changing practice based on research findings and evidence. It has been widely cited that it takes on average 17 years for evidence to be incorporated into routine care [5–7]. Although this number may not be 'evidence-based' and it has been argued that there is a need for improved methods to assess such time lags [5], the core message of a long journey from the production of knowledge until it has become part of routine practice has gained attention. Among others in the early 2000s, Fixsen [8] reasoned that although efforts to develop evidence-based practices and programmes had improved, the science to properly implement these practices was lagging far behind. It, thus, became increasingly evident that new evidence-based interventions do not implement themselves.

Implementation is defined by the Oxford English Dictionary as the process of putting a decision, or plan into effect. Within healthcare, it has been more narrowly defined as "*a planned process and systematic introduction of innovations and/or changes of proven value; the aim being that these are given a structural place in professional practice, in the functioning of organizations or in the healthcare structure*" ([9] p.10). The term *process* is used in both definitions, emphasising that implementation is not an event, but something that takes place over time. The process can be divided into stages, starting with a decision being made to implement the new innovation/change, through early use, full operation and finally reaching a stage where focus in on sustaining use in the long term [8].

Implementation is an essential element of any attempts to improve healthcare because is concerns the actual change of practices [9]. If a new evidence-based clinical intervention is not thoroughly implemented, we cannot be sure to harvest the potential patient or population health gains from the intervention [10]. It has even been argued that using the evidence that we already have would lead to greater benefits than what we could expect from developing new knowledge of clinical interventions [11]. In addition, thorough implementation is important in terms of equity [2] because a clinical intervention must be implemented equally well across relevant

provider settings to be delivered in the same way to all eligible patients, and only then will patients have equal opportunities for benefitting from the treatment.

Implementation Science

Implementation science can be regarded a subfield of health services research and emerged in the 2000s as a response to the challenges of working according to the evidence-based practice concept. Implementation science is often defined as "*the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, to improve the quality and effectiveness of health services*" ([12] p.1).

Implementation science studies are based on the premise that an evidence-based practice is under-utilized [13] but the research can also be more broadly aimed at improving research use in general among practitioners [2, 14]. Thus, these studies differ from other types of clinical or health services trials because the starting point is an intervention that already has a 'proven value' through systematic research. Therefore, implementation studies traditionally are not focused on the impact of the intervention on a clinical (patient) level but rather, it is concerned with measuring improvements at the service (provider) level [15], as illustrated in Figure 1. That is, the outcome of interest is whether the intervention is delivered as intended. Another possible focus is what happens in the implementation process, which precedes improvements at the provider level. Outcomes of interest in studies of the process include whether an intervention has become accepted and adopted, if this is done with fidelity (i.e. the degree to which the intervention has been implemented as intended [16]), and if the efforts are sustained. The appropriateness, costs and feasibility of implementing the intervention may also be measured. Because it is the implementation process that is in focus, implementation studies are concerned with understanding barriers and facilitators for thorough implementation, and evaluation of effective strategies to aid implementation processes [2, 13, 17].



Figure 1. Types of outcomes in implementation research, inspired by Proctor et al. [15].

Theories and Theoretical Frameworks

The process of implementing a clinical intervention can be complex. The complexity arises if interventions consist of multiple components that are to be implemented in a context consisting of several interacting levels and stakeholders [9], for instance patients, healthcare professionals, managers, administrators and politicians, in departments, hospitals and healthcare regions. A broad range of different barriers and facilitators, also called determinants, may therefore affect the success of implementation [2, 10]. Implementation scientists have, by making compilations of the results of several empirical studies and/or previous theories, suggested a number of *frameworks* that organize such determinants into constructs (higher order groups or domains). The frameworks typically consist of four to five constructs [2], including the individual practitioner who is to change his or her practice, strategies used for changing practice, characteristics of the implementation object, and the context in which the implementation is to take place. Patients are part of some frameworks, as their preferences and attitudes may influence implementation. Implementation frameworks can be useful as tools for structured data collections and analysis or when planning, or evaluating implementation. A framework may, thus, aid in organizing data but does so without specifying causal relationships [13, 18].

Theories, on the other hand, give explanations to how constructs are related or how they may influence each other or the output [13]. Theories have an important function in implementation science to provide an understanding of causal mechanisms of implementation [18] and may help explain whether change is possible [19]. Relevant theories may be found in several fields, e.g.

organisational research, psychology, sociology and learning and, in addition, there are specific theories developed within the implementation science field [18].

Implementation Strategies

Strategies have been called "the 'how to' component of changing healthcare practice" ([20] p.1), and, thus, have a very central role in implementation science. Implementation strategies can be defined as methods or techniques that aim to influence individuals, groups and organizations to enhance the adoption, implementation and sustainability of a clinical intervention, programme or practice [2, 20]. There are many different types of strategies that are suggested to work through different mechanisms. For instance, there are educational strategies such as workshops or teaching, that intend to influence the knowledge, skills, self-efficacy, attitudes and motivation among the users of the new intervention and financial strategies, where the incentive/allowance structure is altered to reward implementation or use of a desired practice (or contrarily, financial disincentives for not implementing a desired practice) [21]. Overall, no single strategy seems to be superior to others and most strategies have some effect and a combination of strategies, sometimes referred to as a multifaceted strategy [20], tends to be more effective than a single strategy alone [22]. Matching a strategy to the implementation 'object' (i.e. the intervention, programme or practice being implemented) and context is argued to have the greatest potential to create change [10, 22] but there is still a lack of knowledge of what works, for whom and in what circumstances.

This difficulty of determining strategy effectiveness may be related to a difficulty in applying a strategy properly. Proper application is difficult because strategies are in themselves often complex, consisting of several components that require involvement of multiple factors. Some researchers instead use the concept 'implementation interventions', which may better accentuate the inherent complexity of strategies. However, to avoid confusion with the concept of *clinical* interventions, in this thesis too the concept 'implementation strategy' is used. It has been argued that the elements of complex strategies often are poorly understood and that, for many strategies, there is a lack of instructions or descriptions to guide their use [20]. Indeed, implementation strategies can in many ways be regarded just as complex to implement as the interventions that they are intended to enhance the uptake of, facing more or less the same barriers. Thus, there is no reason to believe that a strategy works just because it is chosen, developed and launched: a strategy in itself often requires careful planning and implementation

[21]. Supporting strategies – or 'co-strategies' may have to be applied. This is illustrated in Figure 2.



Figure 2. Illustration of the use of implementation strategies and possible co-strategies.

In summary, implementation is an important part of all improvement processes to secure that evidence-based clinical interventions are carried out as intended and an assessment of barriers and facilitators for implementation should ideally guide the choice of implementation strategies. Implementation strategies, in turn, are the methods or techniques to support the implementation, and one or multiple strategies may be applied. However, it is not always well understood how to make best use of available strategies, thus hindering optimal effectiveness. Often, an implementation strategy must in itself be implemented.

Cardiac Rehabilitation

A Case of an Insufficient Implementation of Evidence-Based Practice

One of the clinical fields where there has been longstanding challenges to implement evidencebased practice is cardiac rehabilitation [10]. Despite ample evidence for its effectiveness, there continues to be gaps between evidence-based recommendations and practice. Improvements in delivering cardiac rehabilitation potentially have great impact, since cardiovascular disease remain a leading cause of mortality and morbidity worldwide [23] and, thus, is hugely resource demanding [24]. The provision of cardiac rehabilitation in Denmark largely reflects these international challenges [25–27]. This section gives a brief introduction to cardiac rehabilitation, including specific remarks regarding the Danish setting, as this is the main focus in the thesis.

What is Cardiac Rehabilitation?

CR is a multicomponent, secondary prevention intervention that aims to improve health and quality of life among individuals with coronary artery disease, which, despite great advances in treatment, remains a leading cause of mortality and morbidity worldwide [23]. CR can be defined in several ways. The British Association for Cardiovascular Prevention and Rehabilitation (BACPR) provides a definition that combines the key elements:

"[Cardiac rehabilitation is] the coordinated sum of activities required to influence favourably the underlying cause of coronary artery disease, as well as to provide the best physical, mental and social conditions, so that the patients may, by their own efforts, preserve or resume optimal functioning, in their community and through improved health behaviour, slow or reverse progression of disease." ([28]p.1).

As the BACPR definition states, CR programmes take a multidisciplinary and biopsychosocial approach [28], intended to lessen both the atherosclerotic process of coronary artery disease that drive disease progression and the related effects this has on mental and social wellbeing [29]. In guidelines and position statements throughout the world [30], it is recommend that CR encompasses baseline patient assessment, exercise training, health behaviour change and education, lifestyle risk factor management, psychosocial interventions and medical risk management, including blood pressure and cholesterol management and the prescription of cardioprotective medication. In addition, delivery by multidisciplinary teams, long term follow up and audit and evaluation may also be recommended as core components of CR [28, 30]. CR is generally divided into three phases: subacute, post-discharge (outpatient) and long-term maintenance [30, 31]. This thesis will focus on the second phase: Phase II (outpatient) services.

Evidence

There is a substantial body of literature demonstrating beneficial effects and cost effectiveness of CR. In a Cochrane systematic review and meta analysis, it was shown that CR reduces cardiovascular mortality and re-hospitalization in patients with coronary artery disease [32]. It has also been found to improve quality of life [32], physical activity status and to reduce anxiety and depression [33]. CR is shown to be cost effective compared to no CR, where the savings are driven mainly by the reduced risk of subsequent events, hospitalisation, intervention costs and utilities [34].

Existing guidelines and recommendations unanimously describe CR as an essential component in the continuum of care for patients suffering from cardiovascular disease and underscore the importance of multicomponent CR to be offered to all eligible patients. For instance, European guidelines recommend participation in a CR programme with class 1 level recommendations on level A evidence, and delivery by a multidisciplinary team with class 2a recommendations and level B evidence [35], illustrated in Figure 3.

Recommendations for specialized prevention programmes

Recommendations	Class ^a	Level ^b	Ref ^c
Participation in a CR programme for patients hospitalized for an acute coronary event or revascularization, and for patients with HF, is recommended to improve patient outcomes.	I	A	555, 556
Preventive programmes for therapy optimisation, adherence and risk factor management are recommended for stable patients with CVD to reduce disease recurrence.	I	В	557–560
Methods to increase referral to and uptake of CR should be considered such as electronic prompts or automatic referrals, referral and liaison visits, structured follow-up by physicians, nurses or therapists, and early starts to programmes after discharge.	lla	В	557, 558
Nurses and allied health professional led programmes should be considered to deliver CVD prevention across healthcare settings.	lla	В	550–552, 561

^bLevel of evidence.

^cReference(s) supporting recommendations.

Figure 3. Illustration from the European Society of Cardiology guidelines on cardiovascular disease prevention in clinical practice [35].

Settings

Previously, CR was located in the hospital due to concerns about the safety of unsupervised physical exercise in patients recovering from acute coronary events [31]. Today, an increasing proportion of CR services worldwide are being provided in community and home-based settings, where it can be delivered as effectively as in the traditional hospital-based setting [36]. The reasons for this transition are twofold. Firstly, this moves care closer to the patients home, improving patients' access to services and possibly improved participation and patient satisfaction [37]. Secondly, there is a societal push to deliver preventive, non-specialised care in the community and, thus, enable hospitals to allocate their resources to providing more acute and specialized care [38, 39].

The provision of CR in Denmark reflects the global trend of moving care from hospitals to the community level. The healthcare regions (managing the hospitals) held the responsibility for CR, until 2007. In this year, responsibility for CR was split between regional and community level (which in Denmark is provided by administrative entities called municipalities) [40]. The shift, aimed at encouraging prevention and ensuring continuity and quality of care, was a consequence of a large, politically initiated reform of the public sector in Denmark [41]. Whereas hospitals still provide specialized CR services, the municipalities have the main responsibility for providing CR to low-risk patients [42, 43]. In reality, the transition is taking time. Currently, practices vary across the country: while some municipalities now provide full CR programmes for low risk patients discharged from the hospital, others offer part of the services in the hospital and part in the municipality and yet other municipalities still provide all or most of the CR through the hospitals [44].

Evidence-Practice Gaps

Like in other areas of healthcare, there has been increased expectations for CR to be based on evidence since the concept of evidence-based practice gained foothold in the 1990s. When it comes to using the best available scientific evidence in CR, there is, however, vast room for improvement. Despite the ample evidence of effectiveness and cost effectiveness of CR, studies worldwide have consistently documented suboptimal provision of CR on a programme level (i.e. the content of a cardiac rehabilitation program, including structures and processes of care) [45–50]. Danish studies too, conducted in the 2000s, have documented incomplete services and variations in the duration and content of programmes throughout the country [25–27]. These

gaps between evidence-based recommendations and practice are problematic, as inclusion of all recommended components of a CR programme is an essential prerequisite for being able to deliver comprehensive CR to eligible patients. At the time for the initial planning of this PhD study, in 2013, there was a need for an updated and more in depth study of CR at a programme level in Denmark, further motivated by the increased delivery of CR in municipalities at the time.

In summary, CR is a multicomponent intervention supported by robust evidence and recommended as an important part of treatment for patients with coronary artery disease, in guidelines throughout the world. Despite this, there are consistent reports of CR at a programme level not living up to evidence-based standards, thus indicating difficulties of using evidence-based knowledge in real life practices [2]. CR programmes in Denmark mirrors the international situation, with evidence-practice gaps and unwanted practice variations. This has caught the attention of policymakers and, in order to support implementation of improved CR at a programme level across the country, two initiatives have been launched, as previously mentioned. These are described in the following section.

Danish National Initiatives to Implement Cardiac Rehabilitation Services

As a response to the suboptimal quality and equity of CR services in Denmark, two national initiatives have been established and disseminated to spur practice changes [51, 52]:

- a national clinical guideline for CR was developed under the auspices of the Danish Health Authority, as a result of a political decision [53]. It is targeted at both hospitals and municipalities due to their shared responsibility for CR.
- a national clinical quality registry for CR was developed by the Danish Society of Cardiology in cooperation with the Danish Clinical Registries [52]. Use is mandated in hospitals. Municipalities are intended to participate but do not yet, due to technical and legal issues.

Even though the two initiatives were not launched by the same organization, they are interlinked. Registries can be seen as derivates of guidelines and operationalize the recommendations given in guidelines [54]. Together, these two Danish national initiatives define best practice based on evidence, monitor how consistently these practices are implemented in real-life CR services and provide feedback to facilitate quality improvement for the services provided and, in the end, patient care. Moreover, registry data may be used for research purposes and the research may in turn, ultimately, be included in updates of the clinical guidelines [55].

Clinical guidelines and clinical quality registries may be conceptualized as *quality improvement interventions*, as they are planned activities set up in response to concerns about quality, aiming to change practice in multiple sites [56]. They may also be categorized as *implementation strategies*, since they are methods or tools that are launched with the aim of enhancing the implementation and sustainability of an evidence-based clinical intervention (CR) [20, 21]. Both 'quality improvement strategies' and 'implementation strategies' are concepts suitable for adopting in this thesis. We chose to denote them 'implementation strategies' because of an emphasis on the processes of implementing evidence-based practice.

In this section, clinical guidelines and clinical quality registries are described in general terms, followed by a brief overview of the literature regarding challenges of applying these strategies. *The specific contents of the Danish guideline and registry are described in the Methods section.*

Clinical Guidelines

Clinical guidelines are frequently used to support the utilization of evidence-based knowledge [57]. Guidelines summarize best available scientific evidence and are defined as "*systematically developed statements to assist practitioner decisions about appropriate healthcare for specific clinical circumstances*" ([58] Chapter 2). Besides evidence, guidelines also include value judgements regarding benefits and harms of alternative treatment options. Evidence and recommendations taken together provide guidance and support decisions on how to provide healthcare services in the treatment and care of an individual patient [1, 59] but, depending on their aim, they may also include advice about structures and processes of care. By following guideline advice, clinicians make sure to work according to best available evidence and unwanted practice variations may be reduced [1]. It is not mandated to follow the recommendations [51] but it is nonetheless strongly recommended [60].

From an implementation perspective, a guideline can be regarded as an educational strategy aimed at healthcare professionals [61, 62], that is, the proposed mechanism behind guidelines is that they will increase professionals' knowledge about best available evidence and, as a result, lead to a change in practice. In the field of CR, guidelines have been developed worldwide, including in Denmark, since the 1990s [30, 63]. In spite of this, gaps still exist between the evidence base and the implementation of CR (see page 24), suggesting that guidelines have not been very effective at creating the intended change.

Clinical Quality Registries

Clinical quality registries (hereafter referred to as 'registries') are quality monitoring systems that collect standardized information on care processes and patient outcomes at an individual patient level within delimited areas of healthcare, thus making it possible to analyse and compare information within and across units [1, 55, 64]. The aim is to monitor and facilitate healthcare systems to delivering high quality and effective services, meeting evidence-based standards for the benefit of all eligible patients [55, 64]. Registries exist in many countries under various names, e.g. audits, medical registries and clinical databases. Most of them are built on the principles of audit and feedback, which is a frequently applied implementation strategy [65]. Audit and feedback has been defined as method to "collect and summarize clinical performance data over a specified time period and give it to clinicians and administrators to monitor, evaluate and modify provider behaviour" ([21] Add. file 6).

During the audit, the individual professional or unit's performance is measured and then compared to a set of standards or targets [66] which define the boundary between acceptable and unacceptable quality [1]. The results of the audit are then fed back to the individual or unit, and may include recommendations. The feedback may be displayed publicly and, often, includes benchmarking to local, regional or national results and/or to the standards or targets set [21]. Use of a registry in practice can, therefore, be seen as involving two interrelated phases. Firstly, data must be collected and entered into the registry. Secondly, the feedback data are to be applied in quality improvement work.

A number of somewhat overlapping theories propose explanations to the mechanisms of audit and feedback. The basic idea is that information about suboptimal practice, when compared to a benchmark standard, will prompt an action to reduce the discrepancy. However, a number of factors may affect the professional's attention and motivation. *Educational theories* suggest that feedback will, firstly, target the professional's limited ability to assess their own behaviour, thus creating an awareness and, secondly, when that individual receives information indicating that their own practices are different and suboptimal compared to colleagues or guideline recommendations, will encourage them to modify their actions [65, 67, 68]. Communication theories stress the importance of the design of the messages and the credibility of the innovation, as well as the characteristics of the messenger [19, 65, 69]. Kluger and DeNisis' [70] Feedback Intervention Theory suggests that professionals' attention span is limited and, thus, only evidence-practice gaps that receive attention have the potential for change. Feedback works by redirecting the attention. Three factors determine how effectively this redirection of attention occurs; i.) the nature of the task performed, ii.) situational and personal variables and iii.) the characteristics of the feedback itself. Turning focus away from the individual and to the larger setting or context in which the individual professional operates, organizational theories suggest that economic, political, administrative and organizational factors, as well as factors related to patients' beliefs or behaviour may effect change that leads to improvements [19]. Organizational culture and the quality and 'actionability' of feedback reports are some of the important effect modifiers [71, 72].

Challenges to Implementing Guidelines and Registries

It was previously suggested (see page 20) that implementation strategies, launched with the aim to improve clinical practice, need to be properly implemented themselves. The literature points to challenges of implementing both guidelines and registries.

There is a vast body of research highlighting that *guidelines* often fail to influence practice for a variety of reasons [73–75]. Barriers may include factors inherent to a guideline itself, such as its user friendliness, the strength of evidence and the perceived relevance of the recommendations. Barriers may also relate to the environment in which a guideline is applied, for example, hindering organizational structures, service resource limitations and insufficient professional awareness [57, 76]. Most studies of guideline implementation have been carried out in hospital and in primary care settings among general practitioners [77, 78]. Implementation in community-based settings such as municipalities appear to be studied to a lesser extent, but it has been highlighted that use in these settings may also be difficult with varied success and may be lower than that in hospitals [79–83]. Despite these well known challenges of implementing guidelines, they are still produced in vast numbers as pieces in the puzzle to improve quality of

care [76] and the new CR guideline in Denmark is just one of a large number of guidelines. It remains unknown whether the CR guideline is effective in influencing the processes of care in the two settings that it is supposed to influence.

Registries are generally considered valuable in improvement work [84–87] but this view is also debated. A recent systematic review found that few registry studies have been able to show an effect in terms of improved quality of care [88]. According to national evaluations of the Swedish quality registries, registries are not the expected drivers of change [89, 90] and a review on stroke registries was not able to document how data were used in quality improvement [91]. An OECD report on the Danish healthcare system noted that there is little evidence that quality monitoring, as accomplished for instance through registries, is being used to guide and drive system wide quality improvement [92]. Furthermore, coverage rates¹ may be relatively low, even years after introducing a registry [87, 93], data may be incomplete and there may be significant delays in data entry [94]. Indeed, it has been argued that most registries do not live up to the ideal of high-quality data entry and use of these data for quality improvement purposes afterwards [64, 90]. These findings suggest challenges with the implementation of the guidelines and, hence, reduced effectiveness. Some attention has been directed at identifying barriers and facilitators for using data, finding that use depends on a range of aspects, including data relevance [95, 96], quality of data and timeliness of feedback [71, 86], staff competencies, access to sufficient resources, collaboration between stakeholders [90, 95, 97–99] and engagement of both staff and managers [71, 100]. Barriers to and facilitators of collecting and entering data have, on the other hand, received less attention in the literature. Lack of human resources [94], lack of time (including the burden of double data entry) and ambiguity of registry variables [64] have been suggested as factors that possibly hinder these processes. Data collection and data entry are important prerequisites for using data afterwards and more in depth study of this phase of registry use, therefore, seems warranted. Focusing specifically on CR registries, there is a lack of studies of both data entry and data usage. Study of these aspects is recommended due to the likelihood of context specific challenges in this clinical area [2, 17, 64] and the fact that there have been calls for more registries in the field [101–103].

¹ Measured as the number of patients included in the registry divided by the number of patients eligible for inclusion.

There is, thus, a range of factors that may influence implementation of guidelines and registries, some of which are particular to the specific guideline and registry, whilst others are more general [104]. The importance of collaboration within organizations is one of the highlighted aspects. While frontline staff are generally considered to have essential roles to play in quality improvement implementation [105], their perceptions remain largely unexplored within the area of CR. Another staff group of importance are the managers, as they have the formal responsibility for quality improvement [106] and are suggested to have central roles in implementation processes [107–110]. Studies of implementation of quality improvement programs or strategies in other clinical areas have suggested that managers and staff may have different perceptions of an intervention, which may affect its effectiveness [100, 111]. It is not known whether this is the case with regards to registries, neither in general nor CR registries in particular.

Study Rationale

In summary, implementation of evidence-based practice is difficult and CR is an example of a clinical area that lags behind, creating an evidence-practice gap. To improve services, Danish authorities have launched a guideline and a registry, both as strategies to support the implementation of CR in hospitals and municipalities. However, guidelines and registries may be challenging to implement in themselves. While it is well documented that guideline implementation is often limited, it is not known whether the new, politically initiated guideline has changed CR practice in either of these two settings at a programme level. Registries are promising in theory but their value remains unclear, particularly within CR. This may be due to poor implementation. There is a lack of CR registry implementation studies where neither data input, data use or what facilitates use of data for quality improvement has been investigated. Studies of registry implementation seems highly relevant considering the launch of the new Danish registry in this area and, given there have been calls for more registries in this field worldwide, this may be relevant from an international perspective as well.

Aim and Objectives

The overall aim of this thesis was to improve our understanding of the implementation of national clinical guidelines and clinical quality registries for improved CR.

The aim was operationalized by following these three objectives (illustrated in Figure 4):

- to study the service level outcomes of implementation of the national clinical guideline, by determining the extent to which Danish CR services in hospitals and municipalities adhere to national recommendations, just prior to and two years after the publication of the cross-sectorial clinical guideline (**Paper I**).
- to study the first phase of registry implementation, i.e. data collection and entry, by exploring how staff, entering data into CR registries in Denmark and the United Kingdom, perceive the implementation process related to the registries (Paper II).
- to study the second phase of registry implementation, i.e. the use of feedback data, by investigating the extent to which Danish clinical quality registry data was used in local quality improvement work and exploring what facilitates the use of this data, with a particular focus on whether there are differences between frontline staff and managers (Paper III).

Figure 4. Illustration of the objectives and how they relate to a simplified logic model showing the intended outcomes of national strategies for improving cardiac rehabilitation services.



Design and Methods

Design

This thesis was designed to investigate different aspects of implementation of the Danish national clinical guideline and the national clinical quality registry. It also included the British registry for the purpose of comparing and contrasting registry implementation experiences. The thesis incorporates the results of three papers, where each of the studies employed different designs, methods and analyses to address the three objectives.

A brief overview of the papers is provided in Table 1. Paper I and III applied quantitative methodology, and Paper II qualitative methodology. The methods and materials are described in this chapter.

Table 1. Overview of the three papers in the study: aim, study designs, samples, data collection methods, analysis and outcome measures						
	Paper I	Paper II	Paper III			
Aim	To determine the extent to which Danish CR services in hospitals and municipalities adhere to national recommendations just prior to and two years after the publication of the clinical guideline.	To explore how staff, entering data into CR registries, perceive the implementation process related to the registries.	To investigate the use of the Danish clinical quality registry data in local improvement work and what facilitates the use of the data, with a particular focus on whether there are differences between frontline staff and managers.			
Design	Quantitative; follow-up survey study	Qualitative; cross-sectional interview study	Quantitative; cross-sectional survey study			
Sample	Data from 2013 and 2015: Hospitals: N=36. Responses from n=36 (100%) both years. Municipalities: N=98. Responses from n=60 (75%) in 2013 / n=87 in 2015 (93%)	24 informants (frontline-staff and administrative staff) using the registries in Denmark and the UK.	Frontline-staff and managers in hospital departments taking part in the Danish registry. N=175, responses from n=101 (58%)			
Data collection	Web-based questionnaire	Individual, semi-structured interviews	Web-based questionnaire			
Analysis	Inferential statistics	Qualitative content analysis	Descriptive statistics and regression analysis			
Outcome measures	Adherence to guideline recommendations for cardiac rehabilitation	Barriers and facilitators for data entry	Extent of unit's use of data. Facilitators for unit's use of data			

The chapter begins with a description of the case study approach and the cases in this thesis.

The Case Study Approach

Overall, this thesis can be considered as taking a case study approach. Case studies have been described as empirical inquiry, in which the focus is on understanding a contemporary phenomenon (the case) within its real world context [112]. The case study approach is argued to be especially well suited for studying complex social phenomena, where the researcher has little or no control over the events that take place and where it is likely that contextual aspects will influence the case [112]. A case study may be conducted to provide a general understanding of a phenomenon using a particular example, where the case itself is usually of special interest [113]. The study can be explanatory, exploratory or descriptive [112] and the applied methods can be quantitative or qualitative or a mixture of the two. Multiple sources of data may allow for data triangulation [112, 114]. Theory may guide the data collection as it gives direction and structure. During analysis, theory may be used to guide and focus the researcher's attention and search for matching and rival explanations in the patterns of data. The goal is to make analytical generalizations, rather than generalizing in a statistical sense [112].

Case studies do not have to be limited to single cases [113]. In this thesis, an approach with single cases with embedded units is taken, with the purpose of analysing across settings [114]. In Paper **II**, the British registry was included as an additional case which, as recommended in multiple case studies, constituted a different but related case [112] that allowed for studying similarities and differences from an international perspective [114].

The Cases in this Thesis

The Danish case in this thesis represents nationwide efforts to minimize evidence-practice gaps in CR. By choosing this case, it was possible to study the implementation of both the guideline and the registry in real life practice. When studying experiences of using the Danish registry, i.e. the Danish Cardiac Rehabilitation Database (DHRD²) in Paper **II** and **III**, this was undertaken in practice, in all its complexity, to capture outcomes and experiences as they were, without interference from third parties, e.g. researchers. The DHRD registry was studied at different points of time in the initial three years, which is commonly regarded as the time it takes to implement evidence-based practice [8] and also the time expected to implement a registry in Denmark [115]. Both the guideline and the registry are developed as part of larger quality

² In Danish: Dansk Hjerterehabiliteringsdatabase

improvement initiatives in Denmark, following the same procedures and frameworks as other national clinical guidelines and registries in Denmark. The results and findings from this thesis may, thus, be of wider interest. In addition, there were pragmatic reasons for the choice, as it was possible to study the initiatives in a native language, to a low cost, as it was within geographical reach and the organization behind the registry was willing to cooperate in the work.

As previously mentioned, the initial plan was to study the implementation of the DHRD registry in both hospitals and municipalities, as it was intended to be used in both settings [52]. However, due to legal and technical issues, it was not possible for the municipalities to take part in the registry in 2015, when the work on the thesis was initiated. Instead, we included an international case in order to take a broader perspective of the experiences of implementing a CR registry, i.e. from a case that was similar but yet different [112]. We still wanted a CR registry, in order to stay within the same clinical area of focus, but one that was older and, thus, more likely to be further ahead in the implementation process [8]. From an international perspective, few countries have described their national clinical quality registries for CR [94]. One of the countries that has is the UK, having a well established CR registry with voluntary participation; the National Audit of Cardiac Rehabilitation (NACR). We attempted to include NACR in both Papers II and III but, unfortunately, this was not possible. The specific aim of Paper III evolved as a result of the findings during Paper II data collection. By that time, ethics approval in the UK and the survey translation and cultural adaption, necessary to conduct the survey in Paper III, were judged as non-feasible in terms of time and resources, both involving a lengthy process. Paper III, therefore, included only the Danish DHRD registry.

Description of the context is emphasized in both implementation studies and case study approaches, as this contributes to the understanding of the studied phenomena and the possible transferability of findings to other settings [112, 114, 116, 117]. The following are descriptions of the Danish guideline, the Danish DHRD registry and finally the British NACR registry.

The Danish National Clinical Guideline

The Danish national clinical guideline for CR was a result of a Danish political decision, in 2012, to develop guidelines in clinical areas with evidence-practice gaps and large, unwanted practice variations across the country [51]. The Danish Health Authority received a directive to develop these guidelines and CR was identified as one of the first focus areas. The development
of a CR guideline, under the auspices of the Danish Health Authority, represented a shift from the development of previous guidelines, which had been published by medical associations. The new guideline for CR was published in October 2013 and was disseminated to relevant stakeholders. The guideline is targeted at clinicians and local administrators, including recommendations on nine non-pharmacological components of a CR programme, listed in Table 2 [118]. Six of the nine components have 'strong recommendations', which is the highest level of recommendation that can be given. The guideline is delimited to Phase II (outpatient) rehabilitation and, therefore, is to be implemented in both hospital and municipality settings due to the shared responsibility for secondary prevention and rehabilitation (see page 24). Guideline implementation advice was made available on the Danish Health Authority's webpage (www.sst.dk/da/nkr/implementeringshaandbog).

Table 2. Overview of core components of cardiac rehabilitation according to the Danish
national clinical guideline
Core component
1.a. Systematic referral
1.b. Management of barriers to patient attendance
2. Exercise training *
3. Patient education **
4. Psychosocial support
5. Anxiety and depression screening

6. Nutritional counselling
7. Smoking cessation counselling
8. Vocational advice
* Recommended twice a week for 12 weeks, with test before and after using a valid test method
** Sub-components include: cardiac disease and medical treatment; lifestyle, motivation and lifestyle change; psychological reactions; social relations; sexuality and cardiac disease

*** Recommended tool for screening is the Hospital Anxiety and Depression Scale (HADS)

The Danish Registry: The Danish Cardiac Rehabilitation Database

The DHRD was developed and disseminated alongside publication of the national clinical guideline for CR [118], in order to monitor whether guideline recommendations were followed and in order to support improvement of the processes and outcomes of CR [52]. As a secondary aim, it may be used for research purposes. DHRD builds partly on the guideline and, therefore, collects data on quality performance indicators corresponding to some of the guideline recommendations. The registry was initiated by a working group under the Danish Society of Cardiology and approved as a national clinical quality registry by the Danish Health Authority

[52]. DHRD was first launched in 2013 but, due to technical problems, was shut down and relaunched in 2015. Like the other Danish clinical quality registries, approximately 70, it is part of a nationwide quality improvement initiative organized under The Danish Clinical Registries, financed by the Danish healthcare regions [115]. A private vendor manages DHRD's IT platform. The DHRD is governed by an interdisciplinary steering committee and run by the Danish Clinical Registries.

Due to an approval of the DHRD by the Danish Health Authority as a national quality registry, it is mandatory for all hospital departments offering Phase II CR to participate in the registry [52, 115]. Currently, 30 hospitals deliver data, while a few hospitals do not due to different reasons and approximately 5,000 of 11,000 eligible patients were registered in DHRD, in 2017 [119]. The registry is web-based and data collection is a combination of manually entered data (a task performed by clinicians and/or medical secretaries) and automated data capture from patient administrative systems [52]. Data capture has, however, not worked as intended, resulting in double-entry (Lotte Helmark, DHRD steering committee member, oral communication, 2016). Patient reported data are collected through questionnaires and structural data are collected every third year, by means of a survey. User support is available from a database quality manager at The Danish Clinical Registries and a written user's manual is available through the registry's website. Additionally, support is available from the healthcare regions or from local quality improvement units.

Performance on 13 selected process- and outcome indicators (listed in Appendix I) are fed back to the participating departments according to standards determined by the Danish Clinical Registries, through regional web-based information systems (updated monthly) and through annual reports, which are displayed publicly. Data are reported on a local, regional and national level and presented according to standards, allowing for the opportunity of benchmarking and intra and inter site learning. With permission, local data at the individual patient level can be accessed in the regional web based information systems. It is also possible to order specific local reports from the Danish Clinical Registries.

The British Registry: The National Audit of Cardiac Rehabilitation

CR services in the UK are, like in Denmark and many other countries, faced with evidencepractice gaps [28, 48]. NACR was established with the aim to monitor and improve the quality of CR services. In addition, the registry delivers data for research and administrative purposes (www.cardiacrehabilitation.org.uk). The registry was initiated by the BACPR and launched in 2005. The registry is funded by the British Heart Foundation and NHS Digital supports the technology behind this web based registry. NACR is professionally run by a steering committee and administrated by a team at the University of York. Participation is voluntary and units delivering CR in both hospital and community settings may be included. Currently, 224 units have joined, with approximately 101,000 patient entries annually [48]. To encourage and increase participation, a certification programme for CR was recently launched, whereby taking part in the NACR is one of the requirements for certification [28, 120]. Support and a written user's manual is available through the NACR administration and the registry's website.

The data collection is web based and it is decided locally whether this is to be performed by clinical or administrative staff (**II**). There are a relatively large number of variables, but only few are mandatory and those are related to the indicators. As in the DHRD, patient reported data are collected through paper-based questionnaires, while structural data are collected annually.

Until 2015, feedback from NACR was delivered on a national and regional level but since 2016 feedback has been additionally reported at local (hospital / community) level [48]. Feedback is delivered in the form of an annual report, providing data on whether CR services meet a set of national minimum standards (Appendix II) [48, 120]. The standards are based on national recommendations and national outcomes, as measured by the registry. Moreover, annual feedback is delivered on a selection of patient outcome variables, where local and regional results are compared to national average changes [48]. In addition to the annual report, local units can pull pre-defined local reports via the registry's webpage at any time, or request specific, local reports from the NACR administration (Nerina Onion & Corinna Petre, the NACR administrative team, University of York, oral communication, November 2016).

An overview of DHRD and NACR is shown in Table 2. Their implementation, which is the focus of this thesis, may at first glance seem to be at very different stages [8]. However, as NACR enrols units continuously, there will be a number of new units and there will be 'old' participating units working to sustain (or improve) use of the registry. In Denmark, all units were in theory at the same stage of implementation due to mandatory participation but the collected data showed that, in practice, they had come more or less far in the process (**II**).

Table 2. Overview over the two registries: The national cardiac rehabilitation registries in the UK and Denmark (Reference: Paper II)							
	The National Audit for Cardiac Rehabilitation (NACR)	The Danish Cardiac Rehabilitation Database (DHRD)					
Country	The United Kingdom	Denmark					
No. of inhabitants	65.6 million	5.7 million					
Patient groups	Cardiovascular Disease	Coronary Heart Disease					
Registry coverage	National (England, Wales, Northern Ireland)	National					
Overall aim	Monitor and improve quality of outpatient* CR in the UK in order to improve the outcome for patients recovering from cardiac events	Monitor and improve quality of outpatient* CR in Denmark in order to improve the outcome for patients recovering from cardiac events					
First launched	2005	2013 (fully operating 2015)					
First annual report	2007	2016					
Participation	Voluntary	Mandated by Danish law					
No. of participating units	224, hospitals and community	35 hospitals					
No. of patient-level entries (annually)	Approx. 101 000	Approx. 6 000					
Governed by	Steering committee	Steering committee					
Daily management	Administrative unit at the University of York. Team equivalent to 3,5 full time	The Danish Clinical Registries (<u>www.rkkp.dk</u>) The team consists of a manager, quality manager, anidomiologist, and a data					
	manager, training officer, data analyst and a secretary	manager, all of them with responsibility for DHRD as well as a number of other CQRs					
Technical management	In cooperation with NHS Digital	In cooperation with external provider					
Financing (except data collection)	The British Heart Foundation	Government (the Danish regions)					
Financing of data collection and entry	Financed locally by each participating trust	Financed locally by each participating department					
Data collection method	Electronic, web based Patient questionnaires are paper-based	Electronic, web based Patient questionnaires are paper-based					
Data collected and	Clinicians (mainly) or dedicated data	Clinicians (mainly) or secretaries					
entered by	administrators						
User support opportunities	Training sessions, telephone, e-mail, written users manual	Telephone, e-mail, written users manual					
Data linkage	No	Yes (The Danish Civil Registration System; the Danish National Patient Register; the Danish National Database on Reimbursed Prescriptions)					
Patient consent	Opt out model	Not needed according to Danish law					
Programme level data	Collected partly via database, partly via separate questionnaire (annually)	Collected via separate questionnaire (every third year)					
Patient level data	Initiating event, treatment type, lifestyle, medication, demographics, pre-CR clinical outcomes and post-CR clinical outcomes, patient-reported measures	Initiating event, risk factor control, lifestyle, medication, demographics, pre- CR clinical outcomes and post-CR clinical outcomes, patient-reported measures					
Feedback	Annual report; participating units can get their own data via the NACR/NHS Digital database link (with login); programme level data available on general NACR webpage; specific requests on demand	Annual report; participating units can get their own data (monthly updated) through regional clinical management systems (with login); specific requests on demand					
More information available	www.cardiacrehabilitation.org.uk/nacr/	Zwisler et al. Clin Epid 2016:8;451-456					
* Outpatient CR - In Denm	ark Phase II in the UK core/Phase III, the init	tial 8–12 weeks of outpatient CR performed					

at hospitals and community level.

Methods - Quantitative Studies

This section gives a brief overview of the methods and materials used in the two quantitative studies. Please refer to Paper I and Paper III for more detail.

The objective of Paper I was to determine the extent to which Danish CR services in hospitals and municipalities adhere to national guideline recommendations. In order to accomplish this, a quantitative, follow-up survey study was conducted. In Paper III, the objective was to determine the use of registry data and what facilitates use of such data, from the perceptions of both frontline staff and managers. This study was also conducted by means of a survey.

Survey Questionnaires

Both Paper I and III applied existing survey questionnaires, which were modified to fit the settings studied in this thesis.

The survey questionnaire used in Paper I took offset in the *DHRD structural survey*, which was used to collect the hospital level data that we were granted permission to use in this thesis. The questionnaire used in DHRD is a modified version of a previously developed and tested questionnaire that evaluated the content of CR services in Denmark in the 2000s [25, 26]. It surveys different aspects of CR services according to the nine clinical guideline recommendations (refer to Table 2) in four sub-questionnaires, each was distributed to a member of the multidisciplinary CR team (physician, nurse, dietician and physiotherapist) to allow the professionals to respond to questions about their main area of care (for example of nurse questionnaire, see Appendix III). To collect data on municipality level services, the DHRD survey was adapted to the municipality context, e.g. by changing the word 'hospital' to 'municipality' and after a pre-test with minor revisions, it was ready to use.

Paper III used the 'Quality improvement While Adopting Quality registry outcomes survey (QWAQ)', which was developed in Sweden [100]. This generic 50 item survey questionnaire aims to measure aspects of a clinical quality registry and the context that may influence use of registry data in local quality improvement. Hence, the survey included questions about perceived quality of the registry data and organizational conditions for registry work, in addition to seven items covering how and to what extent data are used for local quality improvement work. These seven items form an index constituting the dependent variable. The remaining items form five independent variable indexes and a number of single variables [100].

For the purpose of the thesis, the QWAQ was translated and culturally adapted to the Danish setting (Appendix IV). Recommended methodology with forwards and backwards translation was applied [121] and the translated survey was pre-tested through cognitive interviews [122] among 15 individuals representing the target group (frontline staff, managers and administrators involved in using clinical quality registries) (Paper **III**, additional file 1). The translation and adaption process was not included in the main body of Paper **III**, as it was not part of the initial research question. Rather, it was a necessary step to be able to use the QWAQ in Denmark.

Respondents

The respondents of the survey questionnaires in both Paper I and III were staff and managers working in units providing CR. We strived to include respondents from all units providing CR in Denmark, due to the relatively low number of hospitals (N=36, later reduced to 35) and municipalities (N=98). An overview is presented in Table 3 (including Paper II, described later).

Table 3. Overview of participants in the three studies								
	Hospitals, DK				Municipalities, DK	Hospitals and communities, UK		
	Frontline staff	Nurse coordi- nators	Mid-level managers	Heads of dept.	CR staff and coordinators, municipalities	Frontline staff	Nurse coordi- nators	
Paper I	Х	Х	Х		Х			
Paper II	Х	Х				Х	Х	
Paper III	Х	Х	Х	Х				

In Paper I, *hospital level data* in both 2013 and 2015 emanated from DHRD. DHRD identified respondents for each of the 36 hospital departments (physicians, nurses, physiotherapists and dieticians) by contacting the departments by phone. In the 98 *municipalities*, all these four staff groups are not necessarily represented due to different local organizations of CR services. Therefore, one respondent, employed as a manager or coordinator, responded to all four parts of the questionnaire at baseline. As this proved to be a heavy response burden, we had to change approach at follow-up with up to four respondents in each municipality, corresponding to the approach used in hospitals. These respondents were selected by each municipality following email queries.

In Paper **III**, all hospitals reporting data to DHRD were included (N=30), including both frontline staff entering data (nurses, physiotherapists, dieticians) and managers, as they have responsibility for leading quality improvement work [106]. Mid-level management was represented by nurse managers and leading physicians and department managers represented by leading nurses, leading physicians and leading physiotherapists. Respondents were identified through websites or by direct contact to the department.

Questionnaire Data Collection

The baseline data collection for Paper I took place in 2013, prior to the launch of the national CR guideline and follow-up was two years later, in 2015. The baseline data collection thus took place in the planning phase of this PhD study. The QWAQ data for Paper III were collected between May and June 2018.

For both Paper **I** and Paper **III**, the survey was electronically managed and distributed via email, with up to two e-mail reminders to non-responders. Paper **I** was additionally followed up with a phone call to remaining non-responders and Paper **III** with an e-mail containing one question about the reason for non-response.

Organizational Data

For Paper **I**, organizational data regarding healthcare region, population size in hospital catchment area and degree of specialization were obtained from the healthcare regions' webpages. For municipalities, information about the corresponding healthcare region, classification according to geography (urban/suburban/rural), population size and socioeconomic index was obtained from the Ministry of Social Affairs and the Interior (<u>www.noegletal.dk</u>).

Statistical Analyses

Statistical analyses were performed with SAS version 9.3. and Stata version 15.0. P-values \leq 0.05 were considered statistically significant.

Paper I: analyses included descriptive and inferential statistics. Adherence to each of the guideline recommendations was classified as either 'fulfilled' (i.e. the service is available) or 'not fulfilled', and calculated at the national level as n ('fulfilled') /N. Differences between baseline and follow-up adherence were analysed using Fisher's Exact Test. Municipalities without CR services were excluded from the analyses, and differences between baseline and

follow-up were calculated only for municipalities reporting provision of CR at both time points. The provision at individual unit level (hospitals and municipalities) was calculated as the sum of CR recommendations (min 0, max 7) and quality aspects (min 0, max 6) that were fulfilled for baseline and follow-up respectively. Subsequently, mean scores and standard deviations were calculated. Finally, association between the different organizational aspects of hospitals and municipalities and the number of core recommendations and quality aspects fulfilled at each unit was calculated using Fisher's Exact Test.

Paper III: descriptive statistics characterized respondents. QWAQ item and index scores were calculated as raw scores and as dichotomized scores. The index scores were stratified and presented according to the groups of staff (Frontline staff, Mid-level management, Head of department). Kruskall-Wallis and Wilcoxon signed-rank test was used to investigate if differences existed between groups. Multiple linear regression analysis was used to investigate the factors facilitating use of data for quality improvement work using the index 'the healthcare unit's use of registry data' as the dependent variable and the five other index scores plus one single variable in the QWAQ as independent variables. The regression analysis was performed for the respondents as a whole group, and for staff and managers (the two manager groups merged into one) respectively, to investigate if different factors facilitated use of data in the two groups.

Methods – Qualitative Study

This subsection briefly presents the methods and informants in Paper **II**, while they are described in more detail in the enclosed paper.

To explore barriers and facilitators for entering data into the CR registry, a qualitative, crosssectional interview study was conducted among staff involved in data collection and entry. In this study, both the Danish DHRD and the British NACR registries were included.

Preconception

In qualitative studies, data collection and analysis may be influenced by the researcher's preconceptions. It is, therefore, important to disclose these [123].

I have previously worked as an administrator of a clinical quality registry in Denmark, in a different clinical area. This registry was rather different from DHRD and NACR, which led me

to reflect on different ways of working with the registries. In the course of working with this thesis, I had a position as a secretary for the head of the DHRD steering committee, working with the administration of the DHRD and activities directed to the users in hospitals. In addition to this, in order to prepare myself prior to undertaking this thesis, I participated in CR sessions as an observer in both hospital and community settings and conducted informal interviews with a municipality CR team, staff placed in central positions in regions, staff in quality units at hospitals, and the British NACR team. I did not interview the DHRD team due to my insider knowledge. Furthermore, I had a function as a secretary for the CR interdisciplinary team at the hospital where I was employed whilst working on the thesis, which provided me with valuable insights into the clinicians' perspective.

Based on these experiences and on the literature, I did not expect to see much attention devoted to the implementation of the registry as everyday practice in medical departments is very busy. I did, however, expect to find relatively more attention paid to data entry compared to data utilisation. In order to mitigate the possible influence of my own preconceptions, we used researcher and interpreter triangulation in the qualitative analysis (Paper **II**).

CFIR as a Theoretical Framework

Paper II employed the Consolidated Framework for Implementation Research (CFIR) as a theoretical framework to guide the development of the interview guides as well as the discussion of the findings. This meta-theoretical framework was used to provide an understanding of which important aspects to consider in the implementation of registries. CFIR consists of five major domains that may influence implementation effectiveness: intervention characteristics, outer setting, inner setting, characteristics of the individuals involved and the process of implementation [124]. Each domain, in turn, covers a number of individual determinants, referred to as constructs [124], which can be regarded as independent variables that may influence implementation outcomes [18]. Although the frameworks' constructs may be used as a list for understanding implementation outcomes, a choice of the most relevant constructs, based on careful considerations is recommended by CFIRs developers in order to avoid muddling evaluation [18, 124].

Since there are a large number of implementation frameworks, other frameworks could have been applied as they share both basic properties and aims [18]. CFIR was chosen because of its breadth, emphasizing the multi level influences on implementation and, in particular, because it includes 'the individuals involved' as a separate domain [124] which was regarded important in this study of users' perceptions.

Interview Guide

The interview guide focused on getting the informants to reflect on the registry implementation process and what might have influenced it, as seen from their perspectives. The guide was based on previous literature and empirical knowledge, including the CFIR. The subject was introduced including a definition of implementation as the process from introduction to integration into daily practice. While the first questions were very open, in order to let the informants tell their own experiences as freely as possible, later questions were more specific and theoretically based. The interview guide was pilot-tested and modified further during the first few interviews, taking its final form after two Danish and two British interviews. Both a Danish and an English version were developed to fit the specific contexts (for English version, see Paper **II**, Appendix 1).

Informants and Recruitment

Informants were strategically sampled to represent a wide range of different units and registry experiences, in order to illuminate a range of possible implementation experiences [123]. The units were chosen based on these criteria and knowledge in the research team (DK) and the NACR administrative team (UK). UK recruitment was delimited to England, being the largest country both in size and number of units participating in NACR [48]. In each unit, the coordinating nurse was invited and furthermore asked to invite a colleague with a different background and/or experience with the registry (invitation letter, see Appendix V). To achieve this breadth, 12 informants from each country were recruited.

Data Collection

The interviews were conducted at the informants' workplace alternately in Denmark and the UK, during the period from September 2016 to April 2017. The interviews were conducted in cooperation with a registered nurse who collected data for a masters thesis about nurse

coordinators' perceptions of feedback data³. Our varied backgrounds helped create a relaxed atmosphere in which to conduct the interviews and ensure a thorough coverage of emerging relevant topics.

Qualitative Analyses

Interviews were transcribed verbatim, where the British interviews were transcribed by native English speakers to secure quality. They were analysed using content analysis [125], with an inductive analysis approach [126]. Firstly, the interviews were read carefully and each interview was independently coded by myself and two colleagues. My two co-analysts had different professional backgrounds and different experiences with registries and, thus, viewed data from different perspectives. Secondly, the codes were compared and discussed until consensus was reached. Thirdly, the codes were coded and categorized, constituting the manifest content and, finally, we derived a theme, which captured the latent content of the interviews [125]. The categories and theme are intended to provide an understanding of staffs' perceptions of the implementation process and to illuminate possible barriers and facilitators for data collection and entry.

Ethical Considerations

The study was approved by The Danish Data Protection Agency, Region Zealand, regional approval number REG-149-2015. Use of hospital survey data in Paper I was approved by the steering committee for the Danish Cardiac Rehabilitation Database. Permission to translate and use the QWAQ survey questionnaire in Paper III was granted from the copyright holders (Ann Catrine Eldh and Ulrika Winblad).

The interviewees in Paper **II** were informed about the study orally and in writing, where their voluntary participation and confidentiality was emphasized and they all gave written informed consent to participate. In the survey studies (Paper **I** and Paper **III**), the return of a completed

³ As part of this setup, a minor part of the data concerning the nurse coordinators' perceptions of feedback data was primarily reserved for the purpose of my colleagues' masters thesis and therefore treated separately, to the extent that this was meaningful and practically possible (data not shown in this thesis, but submitted for publication).

questionnaire was regarded as giving consent. The names of the survey respondents and informants were kept confidential at all times.

Results and Findings

This chapter presents the main results/findings from the three studies. Please refer to Papers I-III for specific results.

Paper I: Mapping of CR Services in Hospitals and Municipalities

Participation in the survey was 100 % among the 36 hospitals, in both 2013 and 2015, and for municipalities, it was 82% and 96% respectively. Hospitals were mandated to participate, as this data collection was performed under the auspices of the DHRD in which participation is mandated by law. Municipality participation was voluntary. Responses showed that all hospitals provided Phase II CR during both years and among municipalities, it was 75% in 2013 and increased to 93% in 2015 (p=0.02).

Overall, results indicated that there were still gaps between evidence and practice in CR and, thus, room for improvement, especially in municipalities.

- In *hospitals*, overall fulfilment of the seven measured core guideline recommendations was reported to be high and one significant change was reported: 'anxiety and depression screening', increasing from 61% to 97% (p<0.001) (Figure 5a). An increased number of hospitals offered more core components at the programme level at follow-up compared to baseline; mean rose from 5.5 (SD 0.7) to 5.9 (SD 0.9) (p=0.05), of a maximum score of 7. The quality of the provided services also seemed to improve in the two-year follow-up period, where screening using the Hospital Anxiety and Depression scale (HADS) increased from 25% to 72% (p<0.001) (Figure 5b). Mean scores of the number of quality aspects fulfilled at the individual hospital level increased from 3.4 (SD 1.2) to 3.9 (SD 1.1) (p=0.001), in which the maximum score was 6.</p>
- In *municipalities*, overall fulfilment of the core guideline recommendations was high for the 'exercise training' component, fulfilled by 98%, whereas fulfilment of the remaining six core components was reported to be below 90% (Figure 5a). This was lower than at hospital level. None of the changes indicated in the two-year follow-up period were statistically significant. The individual municipalities' provision of core components also

remained the same in the follow-up period: from mean 4.6 (SD 1.5) to 4.3 (SD 1.3) (p=0.35) of the maximum score of 7. Fulfilment of one quality component 'all components of patient education' was reported to be lower at follow-up than at baseline, decreasing from 51% to 29%, (p=0.04) (Figure 5b). Mean scores for the number of quality aspects fulfilled at the individual municipality level remained the same in 2013 and 2015: mean 2.2 (SD 1.2) and mean 1.9 (SD 1.1) (p=0.35), in which the maximum score was 6.

- Importantly, data indicated considerable variability between units within both hospitals and municipalities.
- Reported provision of CR was neither associated with a hospital's specialization or population size within its catchment area, nor to socioeconomic index or population size in municipalities.
- Regional differences in provision of core components in municipalities and in fulfilment of quality aspects in hospitals were indicated in 2013 but were not evident in 2015.



The * marks the only significant change, which was anxiety and depression screening which increased at hospital level from 61% (n=22) to 97% (n=35), p<0.001 (Paper I).



** marks a significant change at municipality level, decreasing from 47% (n=28) to 37% (n=25) (p=0.04)

*** marks a significant change at hospital level, increasing from 25% (n=9) to 72% (n=26) (p<0.001) (Paper I).

Paper II: Barriers and Facilitators for Registry Implementation

This paper had a particular focus on the data collection and entry process, although it included all aspects of the use of the Danish and British registries, as the different sub-processes of using a registry are strongly interlinked. In total, 24 professionals with varying experiences with CR and the registries were interviewed: 12 in Denmark and 12 in the UK, representing a total of 14 units. They reflected the structure of the multidisciplinary CR teams, with a majority of nurses (half were coordinators), physiotherapists, dieticians, and administrative staff. Physicians were not interviewed because they are rarely directly involved in data collection and entry.

Overall, the analysis indicated both similarities and differences within and between the two registries. One theme and five categories emerged from the analysis, illustrated in Figure 6 below.





- The theme 'Struggling with practices' represented the latent content of the interviews, suggesting that implementation is more complex and demanding than anticipated and it also represents a subtle struggle of raising awareness about the importance of CR, where the registries seemed to be viewed as tools with potential impacts.
- The inductively derived categories covered a range of aspects of importance for registry implementation.
- 'The data entry process' indicated that implementation did not receive much focused attention and that the roles with regards to registry use were often 'naturally' allocated and/or self-defined. Furthermore, it was evident that data entry is an extra task to be fitted into daily practice and may require practice changes.
- 'Resources and management support' highlighted that few had received extra time for data entry but most individuals, although not all, prioritized it. Staff perceived management interest and support as low in the data entry process, but higher in feedback data. Most UK staff had received training while the Danish staff had not.
- 'Registry quality' was important and perceived to be quite high in the UK, but less so in Denmark. The perceived relevance affected motivation. Users in both countries experienced variable ambiguity.
- 'Quality improvement' included both beliefs and experiences. Many Danish users had never seen any feedback. Overall, it was indicated that data were used to a low degree

and mostly for administrative purposes in the UK. High support was expressed for the idea of a registry.

 'The wider healthcare context' emphasized a high level of patient centeredness among informants, where a registry may be perceived as interfering positively or negatively. Documentation and reporting of data was described as part of a culture, which may or may not exist.

Paper III: Using Data from the Danish Cardiac Rehabilitation Database

Responses to the QWAQ questionnaire were received from 101 of 175 (58%), representing 28 of the 30 hospital departments delivering data to DHRD in Denmark. Among respondents, 62 were frontline staff, 20 were mid-level managers and 19 were heads of departments. Most were female (87%) and had three or more years of experience with the registry (68%). Noticeably, almost half of non-responders reported low level of knowledge of the registry as the reason for not completing the questionnaire, and no other explanations were stated as main reasons.

Overall, a relatively low use of data for local quality improvement was reported. Differences between reports from frontline staff and managers were found.

- Not one single frontline staff agreed that they received sufficient resources to analyse data, e.g. time and competencies. To the contrary, 25% of managers stated that they had sufficient levels of resource. While 3% of frontline staff reported having sufficient resources to perform quality improvement work, the corresponding agreement among managers was 35%. Managers found themselves taking part in data analyses and reporting to others more often than frontline staff. Among frontline staff, 26% reported using registry data at a departmental level to identify areas for improvement, whereas the proportions among managers were about twice as high. Overall, 22% of the respondents agreed that taking part in the registry was worth the resources spent.
- For the main outcome measure, the index 'Unit's use of data', the maximum score was 7. Frontline staff scored a mean of 1.3 (SD 2.0), mid-level management 2.4 (SD 2.3) and heads of departments 3.0 (SD 2.5) (p=0.006). This was interpreted as a relatively low use of data.

- Mid-level managers and heads of department had no statistically significant disagreements in responses and, therefore, the two groups were merged into one; 'managers'.
- When regression analyses for the staff and manager groups combined was performed, data quality and usefulness, management request for data and personal motivation was significantly associated with use of data (Table 4).
- As the initial analyses showed differences between the responses of frontline staff and managers, we analysed which aspects were associated with reported data use in the two groups respectively. The results illustrated a difference between the two groups; among managers, data quality and usefulness was significantly associated with use of data and among frontline staff, management involvement in quality improvement work and personal motivation was deemed to be important (Table 4).

Table 4. Associations between Unit's Use of data and indexes in 'Quality improvement While Adopting Quality register outcomes survey' (Reference: Paper III)									
	All respondents			Frontline staff			Managers		
Independent variables	Coeff.	p-value	95% CI	Coeff.	p-value	95% CI	Coeff.	p-value	95% CI
Data quality and usefulness	0.22	0.019	0.04 - 0.41	0.15	0.192	-0.08 - 0.38	0.43	0.027	0.05 - 0.81
Resources	0.28	0.080	-0.03 - 0.58	0.05	0.860	-0.55 - 0.65	0.23	0.276	-0.19 - 0.64
Management request for data	0.40	0.008	0.11 - 0.69	0.28	0.199	-0.15 - 0.67	0.30	0.210	-0.18 - 0.77
Management involvement in quality improvement work	0.46	0.083	-0.61 - 1.19	0.90	0.017	0.17 - 1.63	0.13	0.768	-0.75 - 1.00
Support (agree)	0.46	0.211	-0.27 - 1.19	0.31	0.490	-0.58-1.20	0.87	0.214	-0.53 - 2.27
I am motivated (agree)	1.63	< 0.001	0.89 – 2.36	1.66	< 0.001	0.69 - 2.63	1.10	0.109	-0.26 - 2.47
Model fit (r ²)	0.56			0.49			0.61		

Coeff. = Coefficient; 95% CI = 95% Confidence Interval; r^2 = The percentage of variation in the response that is explained by the model.

Discussion

The overall aim of this thesis was to advance our understanding of the implementation of guidelines and registries for improved CR and three studies investigating different aspects of their use were conducted. This chapter begins with a discussion of the main findings, in light of the existing literature and theories of relevance for interpreting the findings. The discussion is divided into two parts: Part 1 concerns the service level outcomes of the guideline implementation and Part 2 deals with barriers and facilitators in the process of registry implementation. This is followed by a discussion of implications for practice. The final section addresses methodological considerations.

Discussion Part 1: Closing Evidence-Practice Gaps with the Guideline?

Paper I suggested that there are still evidence-practice gaps in CR in Denmark in hospitals and municipalities.

Municipalities

The particularly noteworthy finding in this study was that no overall improvements were found in municipalities in the follow-up period from 2013 to 2015, suggesting that most municipalities did not adapt to following recommendations. Although the guideline was launched to facilitate more evidence-based practices in both hospitals and municipalities [53], it was particularly important to influence the municipalities as many of them were just beginning to deliver CR at the time of this study⁴. In the light of this situation, it is somewhat surprising that they did not grasp the opportunity of adhering to guideline recommendations to develop high quality CR programmes.

As discussed in Paper **I**, the municipalities have only recently engaged in general healthcare quality improvement work [92, 127] and in using guidelines, in particular [79–81, 128], which might explain some of this inertia. However, with reference to previous reports of poor guideline implementation outcomes in hospitals [74] (organisations that, in theory should be

⁴ This was later than other rehabilitation services, due to special considerations to the risks for exercise training without supervision in a cardiac population. Ann-Dorthe Zwisler, The Danish Knowledge Centre for Rehabilitation and Palliative Care, oral communication, 2018)

used to achieving quality improvement using guidelines) experience only provides partial explanation. There is broad consistency from both empirical studies and implementation theories suggesting a range of possible hindering and helping factors related to both the individuals, the guideline in itself, and the context [124, 129]. While Paper I examined the association between size, geography and socioeconomic index of municipalities and CR quality, without finding any links, there are likely other influences from the wider context, such as a basic lack of resources for improving CR (further discussed below in Part 2 of this discussion). There may also be elements of the guideline that are specifically acting as barriers to municipalities [9], indeed this was also suggested in a Danish pilot project of guideline implementation [128]. One such possible barrier is that the definitions of guideline target groups may be too narrow for municipalities. In the case of CR, this would mean that there would be too few patients to create a separate group and, in addition, scheduling these patients in with other local rehabilitation services could provide challenging. Another specific issue was related to the relevance of the evidence behind the guidelines, as staff questioned the evidence base of studies that were conducted in other settings and their relevance in the municipality context [128].

Another possible explanation for the lack of change in municipalities may be that they were not monitoring performance like the hospitals, using the DHRD registry. While the registry was mandated in hospitals [52], the municipalities were excluded from participation due to legislative issues. Since the completion of the data collection for Paper I, municipalities have taken initiatives to monitor CR services themselves, as a means of improving services. For instance, municipalities in one healthcare region (Region Midtjylland) have developed a local registry mirroring the DHRD. Launched in 2017, the first feedback report shows levels of performance that equals those in hospitals [130]. It remains unclear as to whether it is monitoring by means of the registry that has led to such improvement and/or if there are other mechanisms having an impact. For instance, the recent escalation in the transfer of services from hospitals to municipalities [43] has led to an increase in expectations and, therefore, focus on quality in this setting [131].

Hospitals

Results in Paper I indicated that hospital CR services overall were already closer to guideline recommendations than municipality services at baseline, with some positive changes also being

56

indicated in the two-year study period. While these results suggest possible guideline effectiveness in this setting, the observational design of the study cannot rule out that the changes were already under way and/or influenced by factors other than the guideline. As mentioned above, participation in the DHRD registry could be one such factor, however given the fact that the registry was only operating during part of the study period [52] its impact is questionable.

While the observed improvements are positive, the services did not reach their full potential with regards to adherence to guideline recommendations at a programme level. This is unsurprising, given that the existing body of literature suggests that there are challenges facing guideline implementation in this setting [57, 74]. Overall, the findings suggest that there was still room for improvement.

Cross-sectors

Paper I suggested that the gap between hospitals and municipalities overall widened during the study period. This finding was supported by a qualitative evaluation of the different new national clinical guidelines launched by The Danish Health Authority [132]. It found that implementation varied, with indications of less implementation in municipalities and primary care settings than in hospitals [132]. This contradicts the intended outcomes of this large-scale political initiative, as the main objectives of the national guidelines are to contribute to uniform, evidence-based services across settings [53].

The findings point towards a need to support implementation of the guideline. The Danish Health Authority merely disseminated the CR guideline, which is well known as an inefficient strategy if used alone to implement guidelines [133]. A manual for guideline implementation was also made available on the authority's website⁵ but utilization of this manual is dependent upon the local CR units being aware that it exists, and being willing and able to prioritize the necessary resource allocation to use it [134]. The manual includes advice to identify local barriers to implementation, which then should be targeted by tailored strategies. Such work is important, but it could likely benefit from being supported by initiatives at a national level, targeting aspects that are not under the control of local organizations. Identifying which specific barriers would require further study. Some initiatives are, however, already in place. Building on

⁵ https://www.sst.dk/da/nkr/implementeringshaandbog

the national guideline, a set of national recommendations for cross sectorial pathways⁶, health care agreements between regions and municipalities [135] and national treatment protocols⁷ have been developed in a drive towards improving CR implementation. The individual effects and possible synergies between these quality improvement/implementation strategies remain unclear but, as they largely contain recommendations, they may not be sufficient to achieve implementation.

Another strategy aimed at supporting the implementation of guidelines, commonly used internationally, is that of monitoring and feedback by means of registries [134, 136]. Applied at a hospital level and studied in this thesis, implementation of this co-strategy will be discussed in the following section.

Discussion Part 2: What does it Take to Implement a CR Registry?

As argued in the Background, registries are strategies intended to support the implementation of an evidence-based practice, in this case CR. However, to fulfil their aim the registries need to be implemented themselves. The overall impression from the two cases studied in this thesis is that this represents a great challenge, the extent to which is likely underestimated.

This section discusses Paper **II** and Paper **III**: firstly, focusing upon the finding that the use of registry data is limited and, secondly, exploring the possible barriers and facilitators for the whole process of applying registries in practice. Findings from both the Danish and British registries are incorporated in this discussion unless otherwise noted.

Data Use

Starting with the second phase of implementing a registry, i.e. data use, overall, the Danish and British cases both indicated relatively sparse use of data, although it varied between units and may have been higher in the UK. This is based on the interview accounts in both countries and the survey in Denmark (quantitative measures were not collected for the British case). The relatively low use is in line with previous studies, suggesting that, while there are examples of

⁶ In Danish: Anbefalinger for tværsektorielle forløb for mennesker med hjertesygdom. Available at:

https://www.sst.dk/da/sygdom-og-behandling/hjertesygdom/hjertebehandling

⁷ In Danish: Nationale Behandlingsvejledninger

registries that seem to be actively used, the overall picture is that registry data are not used to achieve local quality improvement to any great extent [90, 95, 99].

Notably, 'relatively sparse use' is an interpretation, as there is no agreement as to what extent and in what ways data should be applied in order to achieve the status of being 'used' or 'sufficiently used'. This relates to the concept of implementation fidelity, that is, whether the registry is used in the way the developers intended it to be [16]. As this may not be explicitly stated and as appropriate use may be dependent on the local situation, it can be difficult to assess. The interpretation of findings in this thesis, thus, stems from an evaluation of the current CR practice, where Paper I indicates that there are gaps between recommendations and practice in nearly all Danish hospitals. Furthermore, the latest annual report from the British registry also shows room for improvement [48]. While the QWAQ survey in Paper III measured ways of using data that may be in line with 'traditional' ways of viewing quality improvement in practice, such as identifying gaps compared to standards and benchmarking [1], the British informants in Paper II gave examples of other ways of using data. They had primarily used it to provide data about production for local commissioners, e.g. the number of patients that had attended CR. A few (including one Danish informant) stated that they had used data to put pressure on their local management to invest in CR. This kind of use was not measured in QWAQ, but it might prove helpful in order to improve the quality of CR, which is the ultimate aim of the CR registries.

To our knowledge, a nationwide source, to which to compare QWAQ survey reports, does not exist. Validation of the self-reported responses about how much and for what purposes data were used to achieve quality improvement at a local level was, therefore, not possible. In one of the healthcare regions, however, it was possible to get access to administrative data regarding the number of unique visitors on the DHRD webpages held within the online regional management data information systems (Box 1). Achieving source triangulation in this way offers an opportunity to reflect upon data use, by comparing and cross-checking the consistency of the information derived from the survey with this administrative source [123].

59



Box 1. The figure shows the number of unique visitors to the Danish Cardiac Rehabilitation Database (DHRD) data pr. month in the online management data information system in one of the healthcare regions.

Two incidents possibly effecting use are marked: The red arrows mark the release of the annual report and the yellow dot marks the introduction of a highly resource demanding regional activity, which may have competed for resources and, in doing so, forced other activities, such as improvement work based on the registry, to take a back seat.

As the data indicate 'unique' visitors, it is not possible to know whether data have been copied and distributed to other staff in the same hospital, although this is likely. The user IDs (not shown due to confidentiality) show that data is accessed by slightly more administrative than clinical staff and it is possible to conclude that most staff and managers do not retrieve data from the system themselves, comparable to findings in both Papers **II** and **III**. Not all hospitals in the region had retrieved data regularly in the first half of 2018, as only a few of the departments delivering CR are represented among the IDs of the unique visitors. This supports findings in Papers **II** and **III** of relatively sparse use of data.

Importantly, claiming to use data for e.g. identifying gaps and making inter-site comparisons does not necessarily translate into actual improvements of care. Establishing such an association would require further study, for instance by comparing survey reports to improvements found in the results in the registry. If use of data does not lead to improvements of practice, registries are merely measuring *current* practice. Change may still be seen, since it may take place due to other influences [137], such as economic constraints, campaigns by patient organizations,

research findings (e.g. guidelines), or practice changes necessitated to collect data for entry into the registry (described in Paper **II**).

Barriers and Facilitators for Implementing CR Registries

We now turn our focus to a discussion of what may or may not facilitate the successful implementation of a CR registry, encompassing both entering high quality data into a registry and using these data for local quality improvement. Interestingly, many similarities were found between the two studied cases in Denmark and the UK in Paper **II**, despite the fact that the registries were different in terms of their administration, agreed terms for participation and, not least, their maturity. The informants' 'stories' centred on the same aspects, although their real-life experiences sometimes were quite different. This suggests that there may be common barriers and facilitators for implementing a CR registry across different settings. Furthermore, considerable agreement was found between interview data in Paper **II** and survey data in Paper **III**.

Overall, our findings contribute to the existing body of literature by describing a complex interplay of a number of factors that affect implementation. The following section discusses key selected barriers and facilitators identified in both Paper II and III, applying the determinant framework CFIR [124]. With the interplay of factors in mind, the CFIR allows for a structured discussion around five potentially important types of determinants (labelled 'domains' in the framework) for implementation: the process of implementing, the registry (intervention) itself, the people involved, and the inner and outer settings.

The Implementation Process: need for higher prioritization

In striking contrast to the abundant advice for successful implementation, the implementation of both the Danish and British registry received little attention and focused planning at a departmental level, often with no or few extra resources. A partial explanation could be that the registries were regarded as a relatively "*small thing*" (citation, Paper **II**) among many other activities that received a higher priority. This was found to exist in addition to a more or less explicit lack of resources and defined roles for planning, supporting and executing implementation. The result was that staff were often left to perform the task by themselves. Although staff managed to secure a considerable amount of data inputting, the collected data were sparsely used in the local settings, as indicated in the previous section. In concurrence with the existing body of literature, it, thus, seems like an inexpedient prioritization of resources that

management leaves implementation to staff; staff need management involvement and support in the whole process [95, 97, 98, 107, 108, 138] to achieve both high-quality data entry *and* subsequent use of data.

Intervention Characteristics: continuous improvement needed

Unsurprisingly, a registry's technical quality, clarity of variables, perceived data quality and relevance, adaption to patient pathways and general user-friendliness played a very important role in its usability [71, 97, 138, 139]. This highlights the importance of improving existing registries (if the registry is suboptimal in terms of these attributes) and/or to ensure that these are continually maintained at the highest level [64, 94]. Notably, the British registry seemed to be doing better than the Danish, possibly due to its relative maturity and the differences in the organization of the registry administration. In terms of attributes, the 'relevance' criteria may be particularly difficult to meet, as both this and a previous study indicate that staff have their own perceptions of what constitutes quality in CR [140] emphasising psychosocial aspects of care, in addition to process- and clinical outcomes. Such aspects are potentially difficult to turn into change-sensitive performance measures that would be suitable to use as indicators.

With regards to the delivery of data (considered as an intervention characteristic) from the registry organizations to the end users, the fact that many frontline staff were not provided with any feedback was clearly a barrier to use of data in Denmark and, in some instances, also for the users' motivation to participate. This fact suggests that there is clearly room for improving the information and delivery mode of the data.

Characteristics of Individuals: in general good will but lack of skills

Interestingly, findings of this study pointed to a relatively widespread support of the *idea* of a registry, that is, the registries were believed to have a *potential* to improve CR services for the benefit of patients and in a wider sense to strengthen acknowledgement of CR. This belief seemed to play a significant motivating role in both Denmark and the UK. However, the support of the idea was surprising at first as it contradicted the more negative reports of using the registry in practice. The literature suggest explanation, as it has been argued that performance measurement and auditing have become an institutionalized part of healthcare [141–144]. Power [144] proposed two decades ago that there seem to be an "institutional longing" for auditing, because labelling something as an audit gives authority, a special status, as if it holds some "idealized characteristics". This seemingly still holds true, as the thesis found a more or less

explicit buy-in to the value of monitoring and auditing, being built into the culture in some units, but not others. The finding added explanation to the within-country differences in implementation efforts.

While the motivation to improve was high, knowledge and skills (i.e. competencies) were in general lacking and comparable to previous knowledge [124], this seemed to affect implementation negatively. There were several aspects to this. Firstly, although not often clearly articulated, there was a widespread lack of knowledge among staff of the actual purpose and 'wider context' of the registries, in particular in Denmark, but also among newer users in the UK. Secondly, most managers had limited knowledge about the use of registry in daily practice, suggested by the survey and by the accounts given by staff during interviews. While managers cannot be expected to have a detailed knowledge of data inputting, this may still lead to misalignment with staff with regards to registry implementation [111, 145]. Thirdly, staff in Denmark had not had training in data entry and even though this was not regarded as a problem at first, this clearly became an issue as it negatively affected data quality and, thus, trust in and motivation to use data. The more abundant resources for training and support in the UK minimized this problem in this context. However, findings indicated a need for continuous training and networking about registry use. Fourthly, similar to other studies of quality improvement initiatives [97, 108], competencies of how to apply data in quality improvement work were reported to be relatively low in both Denmark and the UK. Even though personal motivation and support from managers seemed to counterbalance the lack of competencies among frontline staff, at least to some degree, the findings give an overall impression that knowledge and skills would benefit from being improved.

Inner Setting: competing with production priorities

Lack of time emerged as an issue for both data entry and use of data, even though survey data suggested that, to some degree, it could be 'by-passed'. Despite the fact that quality improvement is very high on the political healthcare agenda [106], it is competing with other priorities in healthcare, where production and managing costs seem to win in relative priority over quality improvement. Kirk & Nilsen [146] studied implementation of guidelines and questionnaires in clinical practice and denoted them 'flow-stoppers', as they were found to disturb the flow of patients in an emergency practice. Based on data reported in this thesis, this term seem appropriate to use for registries too. In this flow logic, use of a registry can take place

only when it can be fitted into existing routines, or perhaps even provide immediate improvement of routines (**II**). Data entry may also be encouraged if it produces administrative data as suggested in the UK, strengthening the impression of a focus on production and costs.

Outer Setting: relatively low prestige of CR

While a multitude of factors in the wider setting may influence implementation [124, 147], one aspect identified to be important are discussed in brief here (while other aspects are described in Paper II). This concerns the status or prestige associated with CR as a clinical area. Although prestige is little tangible [148], the sum of knowledge acquired in the work of this thesis strongly suggested that CR is perceived as having a low relative prestige as a clinical field in hospital settings, possibly throughout most of the Western world. This finding has some support in previous research suggesting that its relatively low status may influence the interest in and prioritization of initiatives related to CR services, when compared to other activities [148, 149]. Consequently, this leads healthcare staff with CR as a specialty to fight for increased acknowledgement of their field, for their professionalism and more resources for patient care (II). As suggested above, these findings indicate that a registry is regarded by some to support this endeavour and, therefore, it is welcomed, or at least accepted, even though it may interfere with the daily workflow.

Addressing Barriers to Break – in joint stakeholder effort

In summary, Paper II and III point to a number of determinants for data input and data use which are working together in complex ways, leading to, more or less, successfully implemented CR registries. Usually less. Registries were in a Swedish report once called the 'goldmine' in healthcare [150]. Using that analogy, this thesis has studied goldmines where many of the miners lack knowledge, skills, tools and time to dig out and cash in on the gold and, for most of the time, their managers are busy with projects outside the mine. Although this may be both a simplification and an exaggeration, and although the British 'miners' overall were relatively better off compared to the Danish, the comparison may still be useful. The findings in this thesis combined with the body of implementation and improvement research suggest that CR registries have been launched in settings that are not entirely ready to take them up. Furthermore, the registries (especially the Danish registry) need to improve to be more implementable. These findings point to a number of potential areas for improvement but also a number of barriers that need to be addressed. As these barriers are present in different domains

[124], it will require a joint effort by all stakeholders in order to ensure that the implementation is to succeed.

Implications for Practice

Overall, the findings of this thesis are in line with the literature concluding that evidence and performance data, within themselves, are rarely sufficient to change practice [108]. In an acknowledgement of this, educational strategies are commonly used as 'co-strategies', e.g. in the American 'Get With The Guidelines' programme. In this programme, guidelines and performance monitoring are explicitly connected and the data-platforms are linked with educational activities and decision support tools based on the guidelines. Furthermore, support is available to local units in developing quality improvement programmes [151]. Although such activities would accommodate some of the barriers found in this thesis, the 'Get With The Guidelines' programme faces challenges similar to those found in this thesis, i.e. securing resources on a local level to support staff [151]. Training and support, in addition to evidence and performance data, are all important (and training should still be offered) however, the example illustrates that these aspects alone are insufficient to secure the closing of evidence-practice gaps.

Our findings contribute empirical knowledge to the literature by pointing to barriers specifically related to the implementation of CR registries in the studied cases. Altogether, the findings fit well with what increasingly seem to be the conclusion of studies of complex interventions in complex organizations: the problems – and, thus, the solutions – are multilevel. They include both the innovation, the individuals, the organization and the wider society, where both the explicit and less tangible influences in between these levels may be important [152, 153].

While some of what has been found in this thesis may be regarded as 'old news', it is interesting that initiatives like the Danish CR guideline and the DHRD registry are still launched without the stakeholders taking a more explicit and coordinated responsibility for implementation. There are a number of possible explanations for this. Firstly, this could be due to a lack of awareness of these problems from the outset. Secondly, there may be some seduction in the concepts of 'evidence' and 'audit' [144] that make these strategies seem like 'magic bullets' – a notion that Oxman dismissed more than 20 years ago [61]. Thirdly, engaging the wider system is

challenging and taking a more predictable route of 'doing business as usual' is therefore attractive, despite limited effects.

Recently, an approach has been taken in Denmark to strengthen focus on quality improvement *in general* through the launch of a new national programme for quality, including the training of managers and national indicators, counting a registry 'meta indicator' [106, 154]. The management training element has the potential to positively influence some of the issues raised in this thesis, by contributing to and strengthening the culture for quality improvement within local organisations. The effects of the programme remain to be seen.

Our findings, together with the current body of literature, indicate that new initiatives to support the implementation of the CR guidelines and registries may be considered:

- The need for clearer division of roles and responsibilities for implementation both within the local units and in the wider stakeholder groups may be needed, in combination with increased stakeholder cooperation, as suggested above [90, 95, 155].
- Considerations of whether strategies including patient involvement could be employed to influence implementation [156]: experiences of such strategies are still limited, but may include the involvement of patients in the development/updating of guidelines and registries, or targeted at patients' care seeking behaviour [156].
- Resources in healthcare are limited and the implementation of services that are cost effective is a priority for healthcare organisations. To date, costs-effectiveness information has been explicitly excluded from both guidelines and registries [157], but may become increasingly important in order to prove that CR makes a good 'business case' [34, 157–159]. Costs and the level of resource utilization are likely to become an explicit driver for implementation within healthcare systems faced with limited resources [157, 160]. However, there are clearly many challenges associated with allowing costs to drive improvement in healthcare [157, 158]. A discussion of these is beyond the scope of this thesis.

The findings of this thesis reflect the specific context of the two case studies, therefore transferability to other settings should be considered with care [112, 125]. Among those who may benefit from taking the findings into account are the Danish municipalities. They are in the process of developing their CR services and many have already begun or are in the process of using registries mirroring the DHRD, in order to monitor and improve their CR services [130].

Another potential beneficiary of the findings are the stakeholders within the new Danish Heart Registry (currently under development)⁸, into which all existing heart registries (including the DHRD) will be incorporated. From an international perspective, the financing and organisation of CR registries may differ [94] but similarities exist in the need to ensure that registries are developed and administrated to ensure high quality data collection and usage. Above all, stakeholders in CR should acknowledge how much effort it takes to properly implement both guidelines and registries: this being central to optimising the outcomes of these tools for quality improvement.

Methodological Considerations

In this section, the methods used in the three papers are discussed.

Paper I – The CR Structural Survey

In this follow-up survey, a major strength was the fact that we achieved an almost complete set of survey responses at the hospital level and a high response rate at municipality level. The results can, therefore, be argued to be representative of CR provision in Denmark. This was only possible to obtain due to mandated responses in hospitals [52] but nevertheless this also required reminders. The municipalities participated voluntarily but a general willingness to respond, combined with sending two email reminders and making additional phone calls, made it possible to achieve high response rates.

The survey questionnaire was used to assess whether the CR services on a programme level actually adhered to the recommendations set out in the national clinical guideline for CR. The questionnaire had previously been used at two prior mappings of the Danish CR services in hospitals [25, 26]. As it was adapted to fit the new guideline recommendations and, also, for the purpose of this thesis, to fit the municipalities for the first time, face validity (i.e. whether the instrument looks as though it reflects what it is supposed to measure (www.COSMIN.nl)) was assessed in the target groups, with individuals who were experts in CR. This resulted in a few final revisions. Reliability was assessed by analysing correlation between respondents from the same unit (measured on a few items that were duplicated across sub-questionnaires), which demonstrated a high level of consistency (>90% scores in the same response categories). There

⁸ http://www.rkkp.dk/om-rkkp/drift-og-udvikling/diverse-projekter-og-rapporter/nyt-dansk-hjerteregister/

may have been social desirability bias in responses, as the respondents may have been aware of national recommendations, resulting in overly optimistic reports of their services. This methodological challenge is shared with investigations of CR services worldwide, where survey is a common method for inquiry about service level provision (e.g. [46, 47, 49].

In the municipality survey, the change of respondents from one respondent in a managing or coordinating position used as a baseline, to up to four respondents with different professional positions at follow-up may have had implications for the quality of data [161, 162]. Follow-up results may be more trustworthy as professionals answered questions regarding services in their own area of specialty, whereas the managing/coordinating staff completing the baseline survey may have had less insight into specific care processes. However, possible bias may have been minimized by the facts that, firstly, respondents, at both baseline and follow-up, were encouraged to consult colleagues if they were in doubt and, secondly, there was a considerable overlap of respondents at the two measurement points.

While controlled evaluations of nationwide healthcare interventions are difficult to design [163], the uncontrolled, before-after design had methodological limitations because there was no opportunity for the establishment of causality. Indeed, it would have added an interesting aspect to the study if we had tried to establish causality by adding a control group, if this had been feasible, or by asking supplementary questions within the survey, such as: whether respondents has prior knowledge of the guideline, whether they had consciously worked to follow this guidance, and/or which factors might have otherwise influenced them to change behaviour. These questions could also have been incorporated into the interviews in Paper II.

We do not know if reported services level provision corresponded to the actual delivery of CR. Such construct validity is an important aspect of a questionnaire's quality (www.COSMIN.nl). This was not assessed because objective sources with which to assess the association with the self-reported responses are currently not easily obtainable. Indeed, this was also the reason for conducting the survey in the first place.

Paper II – Individual Semi-Structured Interviews

This study provided insights into the experiences of staff involved in data collection and data entry in both the Danish and British CR registries. We regard it as a strength that the study was designed to include informants from two cases, as this provided insight beyond the single registry.

A purposeful sampling method was used as we sought to enhance our understanding of the implementation processes and, therefore, aimed for a broad representation of informants from the two case registries, thus providing a wide range of experiences [123]. We were able to identify informants with a variety of backgrounds and experiences, ranging from nearly new registry users to staff who had been part of the registries from their beginning. We initially aimed for 12 informants in each country (a total of 24) and easily reached that number, indicating a great interest to share experiences of using the registry, which was later confirmed in most of the interviews. The number of 12 was chosen a priori to collect experiences from staff reflecting a wide variety of backgrounds, and this proved to be sufficient to reach a point where no, or very little, new information emerged (i.e. data saturation) [164]. Nonetheless, it is possible that there are experiences that were not investigated. The fact that the British informants were sampled with the NACR registry's administrations office as intermediaries may have affected the reliability of the results. Although this was a great strength, providing access to informants, some selection bias is also possible, as the NACR staff may have chosen informants with whom they had a good relation. This was limited, however, by the fact that it was decided a priori to use different geographical regions, sizes of settings, informant experiences etc.

In the initial design of the study, it was planned to include mid-level managers as informants. However, due to limited resources we had to prioritize and choose to focus on the staff who were involved in the practical work with the registries. The perceptions of managers is nonetheless regarded as very important as they lead the work and distribute resources to different work tasks [106, 107] and may be included in future studies.

Transparency is an important quality aspect in qualitative studies [165] and we sought to fulfil this throughout the study by producing transparent descriptives at each stage, i.e. the sampling of informants, the interview-guide, the process of analysis, and the way in which the data was presented with examples of coding and citations from the interviews being included [125]. The Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines guided writing of the manuscript.

Credibility is another important quality criterion [123, 165] and we sought to enhance this in several ways. Firstly, by giving accounts of researcher bias including prior experiences and preconceptions (compare to **II** and page 41 in this thesis) [165]. Secondly, the analyses of the

interview data were performed by myself and two colleagues who had different professional backgrounds and experiences and, thus, we each analysed data from a different perspective. Such researcher triangulation is a vital control for selective perception and interpretive bias and we believe that discussions within the group of analysts strengthened insights, sharpened the categorization of data and, thus, may have enhanced the quality of analysis [123, 125]. Thirdly, other sources of data in this thesis (survey data from Paper **III** and the administrative data, Box 1 above) largely affirmed findings from the qualitative interpretations [165]. Although such consistency is no guarantee for achieving credibility in our findings, and inconsistency may actually strengthen insights into variations [123], my realist perspective, nonetheless, interpret this consistency as adding to the plausibility of findings. Fourthly, we used interpretive triangulation, where individuals who were members of the groups from which data were obtained were presented with the findings and could confirm them [123]. This was done informally, during the course of 'normal' conversations and observations [165].

The content analysis was conducted with an inductive approach to stay as close to the informants' experiences as possible. This was according to recommendations when studying areas where there is not a lot of knowledge available beforehand [125, 126, 166]. Theory was applied in the form of the CFIR, to guide interviews and to structure the discussion, including the discussion in this thesis. The CFIR was found useful to guide the construction of the interview guide, as it provided a rather comprehensive list of possible aspects to consider. The CFIR was also used to structure the discussion, where our inductively derived categories could be compared to the established framework. A good match was found, except for the fact that the defined constructs in the 'outer setting' domain were found insufficient to match the findings of more general influences in healthcare. The domain name was regarded as suitable, however, and was therefore used.

Paper III – Hospital Survey of Registry Data Usage

For the purpose of this study, we identified and used the Swedish QWAQ survey. QWAQ was developed as a generic questionnaire for assessing the use of data in Swedish registries [100]. As the Danish and Swedish healthcare and registry systems are relatively similar, it was judged as a potential candidate for use also to survey Danish registry users. Alternatively, a new

questionnaire could have been designed, but this is generally regarded as very resource demanding⁹.

Thus, the QWAQ was translated and culturally adapted to the Danish setting, which proved to be a valuable process as it provided the research team with a nuanced understanding of the survey properties. This sharpened our choices in the analysis phase. For instance, the QWAQ does not include an 'I don't know/not relevant' response category in its four or five point Likert response scales. This was not altered in the Danish version, since the developers requested to retain the original setup but it was noted in the field-test that respondents often marked the neutral response option ('neither agree nor disagree'), at the same time as they verbally stated that they did not know the answer. This made us aware that calculating scores where 'strongly disagree' equals 1, 'disagree' equals 2, 'neither agree nor disagree' equals 3 etc. may yield overly optimistic scores (as a 'I don't know' would erroneously yield a score of 3). Consequently, we chose to dichotomise responses with at cut off at 'Agree', as we trusted the responses marked in the positive end of the scales ('agree' and 'strongly agree'). A possible revised version of the QWAQ may benefit from considering the need for a 'not relevant' and/or 'I do not know' response options to increase reliability.

The survey reached an overall response rate of 58%, which can be considered reasonable [167, 168]. Reaching high response rates in surveys is argued to be increasingly challenging [169] and, indeed, a dedicated effort was needed in this study too in order to achieve this: the response rate was merely 21% after the first invitation (data not shown). Inspired by advice in Dillman's [169] Tailored Design Method about improving the motivation of respondents, separate reminder e-mails were written to frontline staff and managers using different motivational arguments. Even though additional reminders may have further improved response rates [170], this strategy should be used with caution as it may contribute to overall 'survey-fatigue' [169].

Although a high response rate is not necessarily an indicator of overall survey quality [167], low response rates raise concerns about nonresponse bias and the generalisability of study findings. Respondents in this study represented 93% of units delivering CR in Denmark. Among non-respondents, limited knowledge of the registry was reported as the reason for not responding. There was no possibility to assess registry usage patterns among those who did not respond at

⁹ Mogens Grønvold, lecture notes, course in questionnaire development and validation, University of Copenhagen, February 2018.

all. Previous studies of registry data use have suggested that the most active registry users are most likely to respond, meaning that actual use would be lower than that reported [90, 99].
Conclusions

With reference to the objectives of this thesis, the following conclusions can be drawn from the three studies:

- Some improvements in CR services at a programme level in hospitals following the launch of the national clinical guideline was found but no overall improvements in the municipality setting. This suggests that the guideline had overall little impact in municipalities, whereas it may have had an impact on CR services in the hospital setting (I).
- CR services at a programme level in Denmark are highly variable within hospitals and municipalities and the gap between the two settings increased in the first two years following the launch of the CR guideline. This contradicts the guideline's aim of uniform, evidence-based CR services across settings (I).
- Overall, there are still considerable gaps between national recommendations for CR and actual practice at a programme level (I).
- Staff working with the implementation of CR registries in both Denmark and the UK may experience a struggle to collect and enter registry data in their busy daily practice. Implementation often receives little focused attention and staff may lack management support (**II**).
- There were similarities and differences in the staff's experiences within the Danish and British registries and between the two countries. These similarities suggest that there are common implementation determinants for CR registries across settings (II).
- Data from the Danish CR registry were relatively sparsely used for local quality improvement, even three years after the start-up of the registry (**III**).
- Managers reported more use of registry data for local quality improvement on a department level than staff did (**III**).
- A complex interplay of factors seemed to facilitate the use of registry data and different aspects may be important for managers and staff (III).

Further Research

While this thesis indicates that existing CR guideline implementation is suboptimal, new costrategies to implementation should be tested. CR is suggested to make a good business case and adding costing information to guideline recommendations has been suggested to improve implementation [157]. Further studies could test the effectiveness of this strategy in CR guidelines.

The findings in this study suggested that CR professionals find psychosocial aspects of care relevant to the quality of care received in CR, in addition to the existing process- and clinical indicators. It was, however, unclear as to *which* psychosocial aspects are of interest and further studies may strive to uncover this. In the future, such aspects could be relevant to add or replace existing CR registry indicators, thereby increasing the perceived relevance and, thus, the motivation to work with data. Patient preferences may (or may not) overlap with the professionals' perceptions and this is also an area for further study. In addition, further research should study how to convert such aspects into change sensitive performance measures and, subsequently, whether or not the use of such measures in practice will influence the quality of care.

This thesis proposes that CR has a relatively low prestige as a clinical area, influencing the priority to use guidelines and registries aimed at improving services. This idea could be pursued in further studies, conducting a more focused evaluation of how prestige may influence decision-making and thus implementation and resource allocation.

Implementation strategies such as guidelines and registries should be based upon a strong body of evidence. The effectiveness of registries to create change in real-life practice is not yet fully understood and is, therefore, an area that requires further study. This could be conducted in hybrid studies, where strategies to improve the fidelity of registry implementation could be evaluated together with the effectiveness of registry use on the processes and outcomes of CR programmes. Cost-effectiveness of registry implementation remains unstudied, in spite of the potential importance that the use of registries are presented as a strong business case. Cost effectiveness could, thus, be added as a third aspect of study.

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Paper I

Health Policy 122 (2018) 1043-1051



Contents lists available at ScienceDirect

Health Policy

journal homepage: www.elsevier.com/locate/healthpol

Implementation of a politically initiated national clinical guideline for cardiac rehabilitation in hospitals and municipalities in Denmark



Cecilie Lindström Egholm^{a,b,*}, Henriette Knold Rossau^b, Per Nilsen^c, Gitte Bunkenborg^d, Morten Hulvej Rod^e, Patrick Doherty^f, Paul Bartels^g, Lotte Helmark^h, Ann-Dorthe Zwisler^b

^a Department of Medicine, Holbæk University Hospital, Region Zealand, Holbæk, Denmark

^b Danish Knowledge Centre for Rehabilitation and Palliative Care, Odense University Hospital and University of Southern Denmark, Odense, Denmark

^c Division of Community Medicine, Department of Medical and Health Sciences, Linköping University, Linköping, Sweden

^d Department of Anesthesiology, Holbæk University Hospital, Region Zealand, Holbæk, Denmark ^e National Institute of Public Health, University of Southern Denmark, Copenhagen, Denmark

^f Department of Health Sciences, University of York, York, North Yorkshire, United Kingdom ^g The Danish Clinical Registries, Aarhus, Denmark

^h Department of Cardiology, Zealand University Hospital, Roskilde, Denmark

ARTICLE INFO

Article history Received 26 April 2017 Received in revised form 13 July 2018 Accepted 16 July 2018

Keywords: Cardiac rehabilitation Implementation Clinical guideline Quality improvement Hospital Municipality

ABSTRACT

A politically initiated national clinical guideline was launched in Denmark in 2013 to improve quality and equality of cardiac rehabilitation (CR) services. The guideline is to be implemented in both hospital and community (municipality) settings due to shared responsibility for provision of CR services. Little is known about implementation outcomes of a guideline in these two settings. We aimed to study this by determining the extent to which Danish CR services in hospitals and municipalities adhered to national recommendations following the launch of the guideline.

The study employed an observational, longitudinal design. Data were gathered by a questionnaire survey to compare CR services at baseline, measured in 2013 immediately before the guideline was launched, with CR services at a two-year follow up in 2015. All Danish hospital departments offering CR services (N=36) and all municipalities (N=98) were included. Data were analysed using inferential statistics.

Hospitals reported improvement of both content and quality of CR services. Municipalities reported no change in content of services, and lower level of fulfilment of one quality aspect. The results suggest that the guideline had different impact in hospitals and municipalities and that the differences in content and quality of services between the two settings increased in the study period, thus contradicting the guidelines aim of uniform, evidence-based content of CR services across settings

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1. Introduction

Ischemic heart disease (IHD) is a leading cause of mortality and morbidity worldwide [1,2], and is thus extremely costly to health care systems. It is forecasted that the prevalence of IHD and the costs due to the disease will increase substantially in the coming decade calling for immediate health political action [3]. Cardiac rehabilitation (CR) is a structured set of post-treatment services intended to facilitate optimal physical, mental and social recovery, decrease re-hospitalization rates and improve lifestyle and wellbeing in patients recovering from IHD [4-6]. CR interventions have documented beneficial effects [7,8], are considered cost-effective [7], and are recommended by European and American medical societies as part of secondary prevention programs [4,5]. CR is highlighted as one of the important focus areas to reduce cost when IHD is present [3]. Despite this, implementation of CR into practice has often been limited, and CR services as described in evidence-based recommendations remain underutilized [9,10], with marked differences in content and duration of the provided services [10-14]. The provision of CR in Denmark has been similar to that in other

western countries. Although local clinical CR practices have existed

^{*} Corresponding author at: Department of Medicine, Holbæk University Hospital, Holbæk, Denmark and Danish Knowledge Centre for Rehabilitation and Palliative Care, Odense University Hospital and University of Southern Denmark, Odense, Denmark

E-mail address: ance@regionsiaelland.dk (C. Lindström Egholm)

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C. Lindström Egholm et al. / Health Policy 122 (2018) 1043-1051

1044

Table 1

Overview of core components of cardiac rehabilitation and related quality aspects according to the Danish national clinical guideline.

Core component	Quality aspect of core component
 1.a. Systematic referral 1.b. Management of barriers to patient attendance 2. Exercise training 	 Training twice a week for 12 weeks Test before and after exercise training period Valid test method
3. Patient education	All sub-components of patient education included ^a
 Psychosocial support 	_
5. Anxiety and depression screening	Screening with HADS ^b
6. Nutritional counselling	Screening for need of counselling
7. Smoking cessation counselling	Integrated part of services ^c
8. Vocational advice	-

^a Sub-components include: cardiac disease and medical treatment; lifestyle, motivation and lifestyle change; psychological reactions; social relations; sexuality and cardiac disease.

^b HADS= the Hospital Anxiety and Depression Scale.
 ^c Only relevant at hospital level, and therefore not included in the analyses.

in Denmark since the 1970s and recommendations since the 1990s, the progression and uptake of CR has been slow [15]. National surveys from 1999 and 2007 report discrepancies between CR recommendations and the services provided in hospital settings in Denmark [15,16].

In 2007, the responsibility for CR services in Denmark shifted from solely resting with the regional level (responsible for hospital management) to a shared responsibility between regional and local community level (administrative entities called municipalities) [17]. Whereas hospitals still provide specialized services, the main responsibility for rehabilitation lies with the municipalities, with the possibility of outsourcing the services to e.g. regional level. This shift was a consequence of a politically initiated major reform of the public sector in Denmark [18], reflecting the global trend of moving care from hospitals to the local community level [19-21]. However, four years after the Danish reform only half of the municipalities had established CR services [22], and patients in hospitals still experienced incomplete CR services and suboptimal equality of care [23].

In response to the insufficient provision and quality of CR, a national clinical guideline was developed in 2013 by the National Health and Medicines Authority. The guideline was the result of a national political agreement aimed at improving the quality and equality of care [24]. The political involvement represented a contrast to previous recommendations, which were produced by professional associations and regional agencies. The guideline was systematically developed and based on best available evidence. It is targeted at clinicians and local administrators. and encompasses recommendations on nine core components of nonpharmacological elements of CR at both patient and programme level [25] (Table 1). The guideline is restricted to outpatient Phase II rehabilitation, which according to national guidance can be provided by both hospitals and municipalities as a result of the shared responsibility for CR delivery [25,26]. Adherence to the guideline is not mandatory [25], but is recommended by the National Heath and Medicines Authority.

Unfortunately, launch of a guideline does not mean that it is actually implemented. It is well documented that even high-quality guidelines may be difficult to implement [8,27,28]. While setting is a recognized factor affecting implementation [29,30], the majority of guideline implementation studies have focused on the use of guidelines in hospital and primary care (GP) settings [30,31]. Although it has been highlighted that the use of guidelines and similar evidence-based recommendations in community settings may be challenging and varying [32-35], and generally at a lower level than that of hospitals [36], in general less appear to be documented about the implementation of guidelines in community settings or implementation outcomes at regional or community level [31]. Considering this knowledge gap in guideline implementation research, in combination with the hitherto suboptimal provision and inequality of CR services in Denmark, it is highly relevant to investigate whether the new guideline has influenced CR provision in both hospitals and municipalities. Hence, the aim of this study was to determine the extent to which Danish CR services in hospitals and municipalities adhere to national recommendations just prior to and two years after the publication of the national clinical guideline.

2. Methods

2.1. General design

The study is an observational, longitudinal study. Data were gathered by survey to compare CR services at baseline, measured in 2013 immediately before the guideline was launched, with the CR services at a two-year follow up in 2015. All Danish hospital departments offering CR services (\hat{N} = 36) and all Danish municipalities (N=98) were included.

2.2. Hospital-level questionnaire and participants

Data regarding the hospitals' CR services were derived from the Danish Cardiac Rehabilitation Database (DHRD), which collects programme-level CR data routinely, using a web-based questionnaire [37]. The questionnaire is based on a previously tested and applied version [15,16], although it has been modified to cover provision of the nine core components of programme-level recommendations in the new national clinical guideline, listed in Table 1. When indicated by evidence-based recommendations in the guideline, the questionnaire also incorporates questions regarding the quality of the services (Table 1). Furthermore, questions regarding the organization of CR services are included. The questionnaire is divided into four areas of professional responsibility relevant to the multidisciplinary CR team: physician, nurse, dietitian and physiotherapist.

DHRD identified relevant respondents by contacting each hospital department by telephone. A representative with managing or coordinating responsibility from each of four professional groups in the multidisciplinary teams (physician, nurse, dietitian and physiotherapist) was identified for each hospital department.

2.3. Municipality-level questionnaire and participants

National data regarding programme-level CR services are not routinely collected at the municipality level. Therefore, a separate. parallel web-based survey was undertaken by the research group of the present study, covering all Danish municipalities (N = 98). We applied a slightly modified version of the DHRD survey to allow for comparisons between hospitals and municipalities. In the survey questions, the word 'hospitalwas replaced by 'municipalityand a few response options were modified to fit the municipality context. Content validity of the municipality questionnaire was pilot-tested, with minor revisions regarding question phrasing and response categories being applied before use.

Based on experience from practice within the research team, we recognized that there would be organizational differences between hospitals and municipalities regarding staffing in the CR teams.

For instance, physicians are rarely part of the team at municipality level. Therefore, we chose to have only one respondent in each municipality, employed in a leading or coordination position relevant to CR, assuming they would have an overview over the local CR services. The municipalities were contacted by telephone and each asked to select one employee to represent them in the survey. These respondents received the four professionally divided (described above) questionnaires merged into one. However, response times and verbal feedback indicated that the burden on the individual respondent was considerable, and thus, at follow-up two years later the DHRD approach with professionally themed questionnaires was used, with the aim of increasing the response proportions (for distribution of questionnaire items pr. professional group, see Appendix, Table 1). A slightly different approach was used to identify respondents at follow-up. We identified local rehabilitation team contact persons through the Danish national website sundhed.dk, and they were subsequently contacted by e-mail and asked to select respondents When not all four professional groups were present in a municipality, it was decided locally who would answer any remaining questionnaires.

2.4. Data collection process

At both baseline and follow-up, an invitation to fill out the web-based questionnaire was sent by e-mail to the respondents identified at the hospitals and municipalities. Two e-mail reminders were sent. Remaining non-responders were contacted by telephone. The cover letter to the hospital-level respondents included a sentence about mandatory responses because the questionnaire emanated from the DHRD, and hospital participation in DHRD is required according to Danish law. Contrarily, participation for the municipalities was voluntary. The web-based surveys were conducted using Enalyzer Survey Solutions (www.enalyzer.com).

Since adherence to national CR recommendations in two different health care sectors were the focus of the study, additional organizational information was collected to assess possible associations between provision of CR services and different subcategories of hospitals and municipalities. For hospitals, we searched regional information websites for information regarding health care region (a total of five regions), population size in hospital catchment area and degree of specialization (cardiology specialist department yes/no). For municipalities, data regarding organizational aspects included health care region, classification according to geography (urban/suburban/rural), population size and socioeconomic index, which was obtained from the Ministry of Social Affairs and the Interior (www.noegletal.dk).

2.5. Ethics

The study was approved by The Danish Data Protection Agency, Region Zealand, regional approval number REG-149-2015. Approval from The Scientific Ethical Committee was not necessary in this study according to Danish law, since it does not include patient data and is not biomedical with inclusion of human material [38]. Use of hospital survey data was approved by the steering committee for the Danish Cardiac Rehabilitation Database. The names of the survey respondents were kept confidential.

We used the SQUIRE 2.0 recommendations to guide writing of the manuscript (http://squire.citysoft.org/).

2.6. Data analysis

Inferential statistical analysis of responses was conducted with mean and standard deviations used where appropriate. We classified adherence to the core CR recommendations at hospitals and municipalities in 2013 and 2015 as either 'fulfilled' (i.e. the service is available) or 'not fulfilled' (the service is not available) for each of the guideline recommendations. Adherence on a national level was calculated as n ('fulfilled') /N. Municipalities indicating that they had no Phase II CR services were not included in the analyses. As there were very few instances of missing data on single items, this was not adjusted for in the analyses.

Based on the total numbers of fulfilled core CR recommendations and quality aspects, differences between baseline and follow-up adherence were analysed using Fishers Exact Test. Significance tests for difference between baseline and follow-up at municipality level was calculated only for municipalities responding to the questionnaire both years, and who reported provision of Phase II CR both years (N = 49).

The total number of core CR recommendations fulfilled at each hospital and municipality was calculated as a sum (min 0, max 7) for baseline and follow-up respectively, and mean scores (Standard Deviations) were calculated. We analysed fulfilment of the six quality aspects in a corresponding manner.

Finally, we analysed the association between the different organizational aspects of hospitals and municipalities and the number of core recommendations and quality aspects fulfilled at each unit (categorized into low, fair, and high fulfilment) using Fisherś Exact Test due to low numbers. The organizational aspects were categorized for the purpose of these analyses. (For a description, see overview of variables displayed in Appendix, Table 4).

A significance level of 0.05 was applied. SAS version 9.3 was used for the statistical analyses.

3. Results

3.1. Questionnaire responses

Participation in the survey is illustrated in Fig. 1. The DHRD hospital survey reached 100% response proportion at both baseline and follow-up, and all (n = 36) hospitals reported provision of Phase II CR services. Among municipalities, 82% (n = 80) responded in the baseline survey and 96% (n = 94) in the follow-up. In 2013, 75% (n = 60) of the municipalities participating in the survey reported provision of Phase II CR services, whereas the proportion had increased to 93% (n = 87) by 2015, which suggests a significant improvement (p = 0.02).

3.2. Provision of core components of CR according to guideline recommendations

Reported provision of each of the core CR recommendations in the national clinical guideline at baseline (in 2013) and at follow-up (in 2015) is shown in Table 2. According to responses at hospital level, overall fulfilment of the core guideline recommendations was high, except for the recommendations 'anxiety and depression screening' and 'vocational advice'. A significant change was observed from 2013 to 2015 for one of the recommendations. 'screening for anxiety and depression', which increased from 61% (n=22) to 97% (n=35) (p<0.001). Other changes were not statistically significant. At the municipality level, baseline fulfilment of the 'exercise training' recommendation was reported high at 98% (n = 59), whereas adherence to the remaining recommendations was reported to be below 90% and lower than hospital levels. Although some changes were indicated in municipalities in the follow-up, none of these were statistically significant. Sample size (N) differed across the components for municipalities in 2015 due to varying numbers of respondents to the four professionally themed questionnaires.

The data for the total number of core CR components fulfilled at the individual hospital and municipality suggested that none of



Fig. 1. Survey participation in hospitals and municipalities at baseline (2013) and follow-up (2015). * In the 2015 survey of municipalities, 4 thematic questionnaires were applied – see also Methods section. A detailed overview of responses for each thematic questionnaire is reported in Appendix, Flowchart and Table 2.

the hospitals provided all of the measured core CR components in 2013, while two out of the 60 municipalities that reported provision of Phase II rehabilitation did. Interestingly, at follow-up two years later the picture had changed, as two out of the 36 hospitals and none of the participating municipalities reported provision of all of the recommended services (Fig. 2a). Overall, an increased number of hospitals seemed to offer more core components at the programme level in 2015 (mean 5.9, Standard Deviation (SD) 0.9) compared to 2013 (mean 5.5, SD 0.7) (p=0.05). In municipalities, the responses indicate that the overall provision of core components remained the same in the two-year period, with mean 4.6 (SD 1.5) in 2013 and mean 4.3 (SD 1.3) in 2015 (p=0.35). Importantly, the data indicate large inter-site variability within both sectors, and suggest that both improvement and cutback of CR services could take place at the local level.

3.3. Quality of the provided services

The respondents' reports of the quality aspects of services according to national recommendations is shown in Table 2, for hospitals and municipalities respectively. Similar to the provision of core CR components, the quality of the provided services seemed to improve at the hospital level. Screening for anxiety and depression using the Hospital Anxiety and Depression Scale (HADS) increased from 25% (n=9) to 72% (n=26) (p=<0.001) (Table 2). Mean scores of the number of quality aspects fulfilled at individual hospital level indicate that more hospitals fulfilled more quality aspects at follow-up (mean 3.9, SD 1.1) compared to baseline (mean 3.4, SD 1.2) (p=0.001) (Fig. 2b). In municipalities on the other hand, fewer respondents reported fulfilling 'all components of patient education' at follow-up than at baseline, decreasing from

1046

Provision and quality of core components of cardiac rehabilitation in Danish hospitals and municipalities in 2013 and 2015.

	Hospitals 2013 N=36 n (%)	2013 Hospitals 2015 N = 36 n (%)	p-value ^a	Municipalities 2013 N=60 n (%)	Municipalities 2015		p-value ^{a,}
					n (%)	N°	
Core components at programme level							
Exercise training	36 (100 %)	35 (97 %)	1.00	59 (98 %)	64 (96 %)	67	0.20
Patient education	35 (97 %)	35 (97 %)	1.00	45 (75 %)	56 (84 %)	67	1.00
Psychosocial support	32 (89 %)	32 (89 %)	1.00	38 (63 %)	42 (63 %)	67	0.83
Anxiety and depression screening	22 (61 %)	35 (97 %)	<0.001	12 (20 %)	13 (19 %)	67	0.45
Nutritional counselling	35 (97 %)	34 (94 %)	1.00	50 (83 %)	52 (78 %)	67	0.79
Smoking cessation counselling	34 (94 %)	33 (92 %)	1.00	53 (88 %)	58 (82 %)	71	0.39
Vocational advice	4(11%)	8 (22 %)	0.34	6(10%)	9 (13 %)	71	1.00
Quality aspects of core components							
Exercise training 2 days/week for 12 weeks	22 (61 %)	23 (64 %)	1.00	25 (42 %)	24 (36 %)	67	0.68
Test before and after exercise training	33 (92 %)	34 (94 %)	1.00	53 (88 %)	59 (88 %)	67	0.58
Valid test method for exercise training	10 (28 %)	12 (33 %)	0.80	4 (7 %)	5 (7 %)	67	0.68
All components of patient education	25 (69 %)	25 (69 %)	1.00	28 (47 %)	25 (37 %)	67	0.04
Screening with HADS ^b	9 (25 %)	26(72%)	< 0.001	5 (8 %)	8 (12 %)	67	1.00
Dietary counselling screening	9 (25 %)	11 (31 %)	0.79	13 (22 %)	15 (22 %)	67	1.00
Smoking cessation integrated in hospital CR services	14 (39 %)	11 (31 %)	0.62	N/A	N/A	-	-

* p-values for municipalities are calculated for those municipalities who have responded to the questionnaire in both 2013 and 2015 and who have reported Phase II services in both years (n = 49). Provision and quality of core components of CR for these 49 municipalities are displayed in Appendix, Table 3.

^a Calculated using Fishers Exact Test.

Table 2

^b HADS = the Hospital Anxiety and Depression Scale.

^c N varies for components due to varies or responses to different professionally themed questionnaires (see Appendix flowchart). Only hospitals reporting overall provision of Phase II services are included in the calculations.

51% (n = 25) to 29% (n = 14) (p = 0.04) among municipalities participating in the survey in both 2013 and 2015 (N = 49) (Appendix Table 3). For the remaining quality aspects, the reported data suggest no significant changes on an overall level in municipalities in the two-year follow-up period. Similarly, there were no indication of significant changes in the mean number of quality aspects fulfilled at municipality level (mean 2.2, SD 1.2 in 2013, and mean 1.9, SD 1.1 in 2015, p = 0.35). As seen for the core CR components, there was considerable inter-site variability of the quality in both hospitals (1–6 quality aspects fulfilled) and municipalities (0–4 quality aspects fulfilled) (Fig. 2b).

No associations were found between reported provision of CR and hospitalsspecialization or the population size in catchment area, and the same applied for population size, geography or socioe-conomic factors in municipalities (data displayed in Appendix, Table 4). Data did suggest regional differences regarding provision of core components in municipalities in 2013 (p=0.04) as well as regional differences in fulfilment of quality aspects in hospitals in 2013 (p=0.005). These differences were not evident in 2015.

4. Discussion

This longitudinal, real-life study concerning provision of CR services according to national guideline recommendations in hospital and municipality settings in Denmark points towards some improvements at hospital level in the first years following the launch of the guideline, but no overall improvements at municipality level. This finding is important, as it suggests that the guideline did not broadly influence practice at the municipality level, and implies that the gap between the two sectors widened in the study period. This is in contrast to the intended goals of national guidelines: to achieve high-quality, evidence-based care and reduce unwanted practice variations [39].

Our findings are not surprising, adding to the body of previous research indicating that guidelines often are unsuccessful in influencing practice [27,28] unless they are properly disseminated and implemented [40]. While the reported improvements in hospitals indicate that they might have implemented the guideline to some extent, the lack of change in municipalities suggests that the guideline was not implemented in this setting, or at least not sufficiently to track any improvements at an overall level. The causes of the differences in implementation between the two settings were not investigated in this study, but with reference to implementation theories and determinant frameworks, possible explanations may be differences in knowledge, competencies, culture, and resources for quality improvement work [41,42]. Previous evaluations of the Danish healthcare system has pointed to such sector differences, arguing that there has been a strong focus on quality improvement and quality management in hospitals, whereas other healthcare sectors have not engaged in this movement until recently [43,44]. Likewise, a Danish guideline project concluded that while clinical guidelines are well established tools in hospital settings, the use of guidelines in municipality settings is relatively new and generally at a lower level [36].

Although our study indicates possible effectiveness of the guideline in hospital settings, the design was observational, and thus, factors other than the guideline may have influenced the results. Hence, it may be useful to view results from this study in light of previous Danish studies conducted in 1999 and 2007 investigating the provision of CR services at hospital level [15,16], from which questionnaires were utilized in an adapted form in the present study. Our findings indicate a continuation of a positive trend for hospital-level content of services according to recommendations. e.g. for smoking cessation counselling, which was provided by 71% of the hospitals in 1999 and has now reached >90%. Screening for anxiety and depression was established in 24% of the hospitals in 2007 compared to reports of 97% in our 2015 survey (data displayed in Appendix, Table 5). These findings suggest that a persistent, longterm political and professional focus advances practice, and that the improvements seen in our study may be the result of continuous



Fig. 2. (a) Provision of core components of cardiac rehabilitation at hospital and municipality level at baseline and follow-up (%). (b) Provision of quality aspects of cardiac rehabilitation at hospital and municipality level at baseline and follow-up (%).

quality improvement efforts influenced by a number of initiatives. Furthermore, the findings highlight that improvements may take an unexpected long time, and thus, the two-year follow-up period of the present study may have been too short a period to expect improvements. On the other hand, this study does demonstrate some changes, indicating that relatively rapid improvements are possible, assuming these changes were not already under way.

Another possible factor influencing the reported improvements in hospitals could be the introduction of a national clinical quality database for CR. It was launched alongside the publication of the national guideline in 2013, with mandatory reporting for hospitals providing CR services [37]. It has been suggested that routine monitoring of CR service provisions could improve quality and reduce programme variations [11,15,45]. The Danish Cardiac Rehabilitation Database monitors and gives feedback on CR programme and patient level services on selected indicators, mirroring the recommendations in the CR guideline [37]. The results are available to the public through a national website (ww sundhed.dk) and are also part of a national indicator monitoring healthcare quality [46]. Although use of the database thus may have played a role as a quality improvement driver [31,47] for the positive hospital-level development in the present study, further research is warranted to establish this connection. Notably, the database could potentially also explain the some of the difference between hospitals and municipalities, as the municipalities are denied access due to legislation in relation to patient data security.

In our analysis of the distribution of CR services across types and sizes of hospitals and municipalities, we found some regional differences in 2013 but not in 2015. This might be an indication of a growing homogeneity in the content of CR services across the Danish health care regions. With regards to the other studied context variables, the provision of core CR components was evenly distributed at both baseline and at follow-up, corresponding to previous Danish findings [15]. The association between contextual factors and quality of CR has not previously been studied in Denmark. Contextual aspects are considered important in the implementation of change in healthcare [41,48], and it is likely that other factors in the context contributed to an explanation of the observed differences.

Our findings regarding CR provision at hospital level can be compared to those of studies in other countries where clinical guidelines provide recommendations. A recent study of Phase II CR services in New Zealand showed that 94% of hospitals provided CR services, although with variations in delivery and content [11]. An Irish national study [13] and British audits [14,49] also show overall improved programmes with considerable inter-site variations. While the overall picture is similar across countries, direct comparisons of the services are difficult to make due to differences in the health care systems. Nonetheless, these studies reflect our findings of improvement but with varying adherence within a country.

4.1. Strengths and limitations

In this study, we have focused on the implementation outcomes of a new national clinical guideline in both hospitals and municipalities. This is important, as the guideline was part of a larger national political initiative in Denmark, and the documented differences between settings regarding adherence to guideline recommendations may have implications for the future implementation strategies for guidelines targeting multiple settings. At the same time, our study was the first, to our knowledge, to study the nationwide programme level provision of CR covering both regional and community sectors, which is significant in order to provide a complete status of CR services. It is a major strength of the present study that it is based on data from all hospitals providing CR in Denmark. We also reached high response proportions at municipality level (82% and 96% in 2013 and 2015, respectively). The high response proportions make the results representative of CR provision in Denmark. Moreover, the design with continuous follow-up makes it possible to follow the development over time.

Nonetheless, the study also has limitations, which must be considered when interpreting the findings. Firstly, the study was of observational design, meaning that uncontrolled factors may have influenced the results. Although the analysis did account for some of these factors (e.g. population, geography and socioeconomy), and we suggest other possible explanations such as the national quality database, other unknown factors may exist. Because the guideline was disseminated widely across the country by national authorities and professional organizations, it was not regarded feasible to define a control group. Secondly, it was not possible to determine whether the self-reported CR services reflected actual practice, even though content validity of the questionnaires was pilot-tested presenting good inter-rater correlation between respondents from the same institutions (data not shown). Thirdly, as with other subjectively reported data, social desirability bias may be present, meaning that respondents were likely aware of the recommendations and therefore inclined to be overly optimistic when reporting local programme content. Fourthly, in the municipality data collection, the use of only one respondent at baseline and one to four respondents with different professional backgrounds at follow-up may well have affected the quality of the answers [50,51]. A possible consequence of this split to professionally themed questionnaires could be more accurate answers due to access to knowledge, compared to responses provided by a single respondent with coordinating or managing responsibilities. Yet, the overlapping of respondents at baseline and follow-up and, furthermore, the encouragement of respondents to ask colleagues when in doubt, is likely to have minimized the possible bias. Finally, when searching the literature about community-based implementation, we recognized that the term is used with different meanings, thus challenging a thorough overview of studies focusing on administrative healthcare entities that resemble municipalities.

4.2. Perspectives

Although research has documented that imperfect adherence to clinical guidelines is common, the relatively poor implementation outcomes of the national clinical guideline suggested by this study, in particular at community level delivered by municipalities. is important knowledge for the policymakers initiating the guideline, but also for guideline developers and local managements. The guideline studied in the present project was part of a political initiative, developing and launching 50 national clinical guidelines under the auspices of the National Health and Medicines Authority over a 4-year period to the cost of 80 million DKK (10.7 million Euro) [24]. The funding was recently extended until 2020 with another 38 million DKK (5.1 million Euro) [52]. It seems highly relevant that this investment is fruitful beyond producing high-quality guidelines, and the national authorities emphasize that implementation is crucial to their effectiveness. A qualitative mid-way evaluation report of this large-scale initiative however suggests varying implementation successes, with the least positive effects in the municipalities and primary care sector [53]. The evaluation thus supports findings of the present study, and strengthens the impression that implementation outcomes in different settings may vary. This seems particularly important to note, as one of the main objectives with the national guideline is to contribute to uniform, evidence-based content of services across settings. As pointed out in previous studies [54], it seems necessary to supplement the dissemination of national guidelines by applying supportive implementation strategies tailored to meet the different contexts of hospitals and municipalities. For the national CR guideline, specific barriers for implementation in both hospitals and municipalities could be further investigated [36,55], and particular attention to 'what works' in the high-performing settings may be worthwhile [31].

While this study was performed in Denmark, the trend of moving care to the communities is international [19] and also encompasses rehabilitation services. The World Health Organization recommends rehabilitation services to be provided in both hospital and communities to ensure timely interventions, access to services and possibly improved patient satisfaction [56]. The need for ensuring availability of evidence-based, equitable CR services in multiple settings thus seems a contemporary worldwide challenge [56]. The present study suggests that use of clinical guidelines to support this endeavour requires careful consideration of the challenges that may present when implementing them, as they may otherwise prove not to be the expected drivers of change.

In Denmark, the movement of CR services from hospital to municipalities recently got a push forward by the launch of national recommendations regarding how to organize CR cross-sectorial patient pathways, which emphasizes that CR services increasingly should be carried out in the municipalities [26]. This has fuelled the ongoing debate of where services are best provided, since not all professionals agree and are calling for evidence of the quality and equality of municipal CR services [57]. The results of the present study could be regarded as an argument against moving CR services to the municipalities. However, while sparsely documented, the development of quality improvement initiatives in the municipalities seem to be moving fast forward [34]. For instance, local databases mirroring the national CR database were implemented in 2017 by some municipalities, documenting levels of performance equal to those of hospitals [58]. The fact that more municipalities reported provision of CR services in our follow-up survey strengthens this picture of increased focus and activity in municipalities. a trend also documented in a British community health services context [59]. Results should be interpreted in the light of this rapid development, and the present study places emphasis on continuous monitoring of the content and quality of CR services across sectors.

In the Danish context, our results contribute to improved understanding of the current deficiencies in core components of CR programmes, which may aid the design of specific national improvement initiatives. In a wider perspective, measuring structural components is important as part of prognostic data necessary to make analyses of patient level outcomes [60], and this study has demonstrated a cheap and feasible way to collect data on structural aspects of care that can serve as an inspiration for rehabilitation programmes across countries and CR registries, which have achieved growing international interest during the recent years [61,62].

5. Conclusion

This follow-up study investigating adherence to Danish national clinical guideline recommendations, specifically content and quality of CR services in both hospital and community (municipality) settings, indicates overall improved adherence in hospitals,

whereas no such general improvement was seen in municipalities. Our results thus suggest that this politically initiated guideline possibly has affected CR services in hospital settings, while to a lesser extent the municipality settings. Although data indicate considerable inter-sitevariation, overall, there seemed to be a widening gap in content and quality of provided services in these two health care sectors sharing responsibility for CR provision in Denmark. This contradicts the guidelines aim of uniform, evidence-based content of CR services across settings. Even though national clinical guidelines are important in summarizing best evidence and providing recommendations, it seems necessary to supplement their dissemination by applying setting-specific initiatives to support the implementation, and thus generate improved CR services in both hospitals and municipalities.

Authors' contributions

CLE drafted the manuscript, and together with HKR and ADZ conducted the survey and analyzed data. All authors contributed to the design of the study and the content of the manuscript. The final version of the manuscript was approved by all authors.

Conflict of interest

The authors declare that there are no conflicts of interests.

Acknowledgements

The authors would like to thank the survey respondents at hospitals and municipalities for their time and effort in filling out the questionnaires. We would also like to thank Carina Bruun Henriksen and Maryam Pedersen who participated in the organization of the survey. Finally, many thanks to the DHRD steering committee for giving permission to use the hospital survey data.

This work was supported by the Department of Medicine, Holbaek University Hospital, Region Zealand; and The Danish Knowledge Centre for Rehabilitation and Palliative Care, Odense University Hospital and the University of Southern Denmark. The funding institutions had no role in study design, in the collection, analysis or interpretation of data, or in writing of the manuscript.

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.healthpol.2018

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C. Lindström Egholm et al. / Health Policy 122 (2018) 1043-1051

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Paper II

"Struggling with practices" – A qualitative study of factors influencing the implementation of clinical quality registries for cardiac rehabilitation in England and Denmark

Authors:

Cecilie Lindström Egholm ^{1,2}, Charlotte Helmark ³, Patrick Doherty ⁴, Per Nilsen ⁵, Ann-Dorthe Zwisler ¹,Gitte Bunkenborg ⁶

Affiliations:

¹ The Danish Knowledge Centre for Rehabilitation and Palliative Care, University of Southern Denmark and Odense University Hospital, Southern Region of Denmark. Vestergade 17, 5800 Nyborg, Denmark. <u>ance@regionsjaelland.dk</u> and <u>ann.dorthe.olsen.zwisler@rsyd.dk</u>

² Dept. of Medicine, Holbaek University Hospital, Smedelundsgade 60, 4300 Holbaek, Region Zealand, Denmark. <u>ance@regionsjaelland.dk</u>

³ Dept. of Cardiology, Zealand University Hospital, 4000 Roskilde, Denmark. <u>kche@regionsjaelland.dk</u>

⁴ The National Audit of Cardiac Rehabilitation, Department of Health Sciences, Seebohm Rowntree Building, University of York, Heslington, York, YO10 5DD, UK. <u>patrick.doherty@york.ac.uk</u>.

⁵ Division of Community Medicine, Department of Medical and Health Sciences, Hus 511-001, ingång 76, plan 13, Campus US, Linköping University, 58183 Linköping, Sweden. <u>per.nilsen@liu.se</u>.

⁶ Dept. of Anaestesiology, Holbaek University Hospital, Smedelundsgade 60, 4300 Holbaek Region Zealand, Denmark. <u>gibu@regionsjaelland.dk</u>.

Contact author:

Cecilie Lindström Egholm, Department of Medicine, Holbaek University Hospital, Smedelundsgade 60, 4300 Holbaek, Denmark. E-mail: <u>ance@regionsjaelland.dk</u>, phone: +45 2497 5436.

Keywords (3-10 words)

Clinical quality registry, clinical audit, quality improvement, implementation, data entry, cardiac rehabilitation

ABSTRACT

Aim

The use of clinical quality registries as means for data driven improvement in healthcare seem promising. However, their use has been shown to be challenged by a number of aspects, and we suggest some may be related to poor implementation. There is a paucity of literature regarding barriers and facilitators for registry implementation, in particular aspects related to data collection and entry. We aimed to illuminate this by exploring how staff perceive the implementation process related to the registries within the field of cardiac rehabilitation in England and Denmark.

Methods

A qualitative, interview-based study with staff involved in collecting and/or entering data into the two case registries (England N=12, Denmark N=12). Interviews were analysed using content analysis. The Consolidated Framework for Implementation Research was used to guide interviews and the interpretation of results.

Results

The analysis identified both similarities and differences within and between the studied registries, and resulted in clarification of staffs' experiences in an overarching theme: 'Struggling with practices' and five categories; the data entry process, registry quality, resources and management support, quality improvement and the wider healthcare context. Overall, implementation received little focused attention. There was a lack of active support from management, and staff may experience a struggle of fitting use of a registry into a busy and complex everyday practice.

103

Conclusion

The study highlights factors that may be important to consider when planning and implementing a new clinical quality registry within the field of cardiac rehabilitation, and is possibly transferrable to other fields. The results may thus be useful for policy makers, administrators and managers within the field and beyond. Targeting barriers and utilizing knowledge of facilitating factors is vital in order to improve the process of registry implementation, hence helping to achieve the intended improvement of care processes and outcomes.

BACKGROUND

The use of clinical quality registries (CQRs) is a common strategy to monitor and improve quality of services and care. A CQR, i.e. a structured collection of data on individual patient level within a specific area of health care, is aimed at monitoring and supporting health care in delivering high-quality services for the benefit of all eligible patients [1, 2]. A registry is intended to affect local practice by providing information about processes and clinical outcomes of care, indicating which aspects that need to be improved, and the feedback is supposed to facilitate quality improvement in the provider organisations [3]. In a national perspective, a CQR enables providers and stakeholders to evaluate performance and improvement against national level quality data [4].

While promising in theory, studies cast doubt on the potential of CQRs as tools in the improvement of care, pointing to several challenges. These include low perceived relevance of data, issues regarding how and when feedback is given, lack of know-how and resources for improvement activities, and poor collaboration between stakeholders [1, 4–8]. Furthermore, low data quality has been pointed out as a major barrier for use of data [1, 2, 9], and delays in data entry [10] and suboptimal coverage have been reported even in relatively mature registries [11].

Although there are multiple possible explanations for these challenges, they indicate problems with the implementation, i.e. the process of putting a CQR into practical use, from the initial startup to the continuous use of data for local and national quality improvement. Poor implementation has been identified as a common problem [12], resulting in suboptimal effects of new practices [13].

For CQRs too, proper implementation is crucial if they are to reach their potential as tools for quality improvement. To date however, implementation of CQRs has received scant attention in the literature. Within the field of implementation science, it has been emphasized that knowledge about context-specific determinants (i.e. barriers and facilitators) is important when

105

planning initiatives to support implementation [14, 15]. While determinants for *use of data* has received some attention in CQR studies, there has been no detailed investigation of possible barriers and facilitators for *data collection and entry*, which constitute the fundamental first phase of CQR implementation. Although it has been highlighted [10] that participating healthcare providers are challenged by additional costs and workloads, and that delays in data entry are common, there is still limited understanding of what may actually help and hinder the process. In order to illuminate this, the purpose of this study was to explore how staff, entering data into CQRs, perceive the implementation process related to the registries.

Setting

We studied the implementation of CQRs within the field of cardiac rehabilitation (CR), which is a structured set of post-treatment services aimed at improving health and quality of life for patient with heart disease [16]. CR has documented beneficial effects and is an important part of treatment in cardiovascular diseases [17–19]. Despite this, studies have documented a gap between the use of evidence-based recommendations for CR services and clinical practice [17, 18, 20–22]. As a strategy to overcome this gap, a number of CQRs for CR have been developed across the western world [10, 23] and further development of registries and data-driven improvement of CR has been called for [2, 22–25].

METHODS

Two case registries

For the purpose of this study, the national cardiac rehabilitation CQRs in the UK and Denmark were used as cases. By choosing these registries, we were able to study implementation of a mature (the British) and a relatively new (the Danish) registry in two different countries and with different incentives for registry participation (voluntary and mandatory, respectively) [26, 27]. Funding and administration also differ. Similarities include scope and design of the registries, with variables being partly based on common European guidelines on CR, as well as largely similar data collection and data entry processes (**Table 1**).

Dennark		
	The National Audit for Cardiac Rehabilitation (NACR)	The Danish Cardiac Rehabilitation Database (DHRD)
Country	The United Kingdom	Denmark
No. of inhabitants	65.6 million	5.7 million
Patient groups	Cardiovascular Disease	Coronary Heart Disease
Registry coverage	National (England, Wales, Northern Ireland)	National
Overall aim	Monitor and improve quality of outpatient* CR in the UK in order to improve the outcome for patients recovering from cardiac events	Monitor and improve quality of outpatient* CR in Denmark in order to improve the outcome for patients recovering from cardiac events
First launched	2005	2013 (fully operating 2015)
First annual report	2007	2016
Participation	Voluntary	Mandated by Danish law
No. of participating sites	224, hospitals and community	35 hospitals
No. of patient-level entries (annually)	Approx. 101 000	Approx. 6 000
Governed by	Steering committee	Steering committee
Daily management	Administrative unit at the University of York. Team equivalent to 3,5 full time	The Danish Clinical Registries (<u>www.rkkp.dk</u>) The team consists of a manager, quality
	employees consists of a project lead, manager, training officer, data analyst and a secretary	manager, epidemiologist, and a data manager, all of them with responsibility for DHRD as well as a number of other CQRs
Technical management	In cooperation with NHS Digital	In cooperation with external provider
Financing (except data collection)	The British Heart Foundation	Government (the Danish regions)
Financing of data collection and entry	Financed locally by each participating trust	Financed locally by each participating department
Data collection method	Electronic, web based Patient questionnaires are paper- based	Electronic, web based Patient questionnaires are paper-based
Data collected and entered by	Clinicians (mainly) or dedicated data administrators	Clinicians (mainly) or secretaries
User support opportunities	Training sessions, telephone, e-mail, written users manual	Telephone, e-mail, written users manual
Data linkage	No	Yes (The Danish Civil Registration System; the Danish National Patient Register; the Danish National Database on Reimbursed Prescriptions)
Patient consent	Opt out model	Not needed according to Danish law
Programme level data	Collected partly via database, partly via separate questionnaire (annually)	Collected via separate questionnaire (every third year)
Patient level data	Initiating event, treatment type, lifestyle, medication, demographics, pre-CR clinical outcomes and post-CR clinical outcomes, patient-reported measures	Initiating event, risk factor control, lifestyle, medication, demographics, pre-CR clinical outcomes and post-CR clinical outcomes, patient-reported measures
Feedback	Annual report; participating sites can get their own data via the NACR/NHS Digital database link (with login); programme level data available on general NACR webpage; specific requests on demand	Annual report; participating sites can get their own data (monthly updated) through regional clinical management systems (with login); specific requests on demand
More information available	www.cardiacrehabilitation.org.uk/nac r/[27]	Zwisler et al. Clin Epid 2016:8;451-456 [26]
* Outpatient CR = In Der performed at hospitals as	nmark Phase II, in the UK core/Phase III: nd community level.	the initial 8–12 weeks of outpatient CR

Table 1. Overview over the two cases: national cardiac rehabilitation registries in the UK and Denmark

Design and participants

The study was qualitative, based on semi-structured interviews aimed at gathering meaningful data about perceived barriers and facilitators to implementation and registry use among staff involved in collecting and/or entering data from sites using the two case CQRs [26-27]].

An apparently similar intervention may be implemented and accepted in different ways in different settings [30]. Accordingly, several sites were included in this implementation study to capture diversity, which may lead to a broader understanding [31]. We sampled our informants with the aim of maximal variety, based on professional background, years of experience with CR, years of experience working with the CQR, type of hospital (university/non-university), geography (suburban, urban, capital) and organization of data entry (clinical staff and/or admin staff). In the UK, we chose to focus on England, as the countries in the UK are organized differently and England is the far largest country, also in terms of participating sites [32].

The informants were identified by contacting the coordinating nurse at the chosen sites by email, explaining the purpose and format of the interview. They were asked to participate themselves and to invite a colleague with a different background and/or experience with the registry. All approached by an enquiry to participate agreed, except for one of the Danish (who had no time) and two of the English (who felt too unexperienced using the registry). Other clinicians with a similar background were then approached, and agreed to participate.

Interview guide

The interview guide was based on theoretical and empirical knowledge about factors associated with successful implementation, including the Consolidated Framework for Implementation Research (CFIR) [33]. Inspired by previous knowledge, we strived to keep the interviews open to let the informants tell us as freely as possible about important aspects of implementing the registry seen from their point of view. Our definition of implementation as "the planned and

108
systematic introduction of the database, with the aim to integrate the use of it in daily practice" was explained to all informants in the introduction. Following this, the opening question was "Tell us about your department's implementation of [the registry's name]". If not mentioned, we probed for perceptions of the process which could illuminate hindering and helping factors. The subsequent questions were theory based and more specific.

The interview guide was pilot-tested, and a few questions were modified after four interviews, as the interviewers' knowledge about the studied area evolved. There were Danish and English country-specific versions of the interview guide, as a few questions needed to be modified to suit the specific context (English version provided in **Additional file 1**). Supplementary field notes were written after each interview.

Data collection

We conducted the interviews at the informants' workplaces for their convenience, except for one interview, where the informant had to stand in for a sick colleague at the day for the interview and later chose to answer the questions in writing.

The interviews were conducted by the first and the second author, with one being the interviewer, introducing the interviewers and the study aim; the other observing, taking notes and making sure the questions in the interview guide were covered. Roles shifted between interviews. The first author has a theoretical /administrative background, with practical experience conducting interview-based research and working as an administrator for a CQR in another clinical field. The second author is a nurse with expertise in CR, working with the registry in practice, and a member of the steering committee for the Danish Cardiac Rehabilitation Database. Due to her clinical role, she knew some of the Danish informants beforehand, and in order to avoid bias, acted as the observer during these interviews. The combination promoted a good relation to the informants, as they had the clinical expertise and registry experience in common with one interviewer, counterbalanced through the naïve perspective on CR and registry use in practice by the other interviewer.

Ethics

The study was approved by The Danish Data Protection Agency, REG-149-2015. No ethical approval was necessary according to laws, since it is not a biomedical study with inclusion of human material (Denmark), and did not include patients (the UK). All informants gave oral and written informed consent prior to onset of the interviews, including permission to audio record the interview. Data were treated confidentially.

Data analysis

All interviews were transcribed verbatim and analysed using content analysis, inspired by the methodology presented by Graneheim & Lundman [31]. Content analysis has been described as a method for making replicable and valid inferences from data with the purpose of providing knowledge, new insights and practical guide to action [34]. In order to let the analyses reflect the informants' perceptions as truly as possible we chose an inductive analysis approach, that is, with codes derived from the interview transcripts [35]. Three of the authors (first, second and last author) separately coded the interviews, and later discussed the codes, which had only few discrepancies, until reaching consensus for all codes. The codes were sorted and combined into subcategories and categories, constituting the manifest content (examples are presented in **Additional file 2**). The process of combining codes into categories was performed by the first and the last author, continuously reflecting on and discussing choices. Finally, a theme was derived, capturing the latent content of the interviews. Altogether, the categories and theme provide an understanding of staffs' perceptions of the implementation process and illuminate

The Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines were used to guide writing of the manuscript [36].

possible barriers and facilitators for data collection and entry.

RESULTS

Informant characteristics

We interviewed 12 Danish and 12 English professionals, reflecting the multidisciplinary composition of the CR teams. They were either nurses, physiotherapists, dietitian or administrative staff, although the majority were nurses, as this is the main professional group collecting and entering data. Half of the nurses had a responsibility for coordinating the CR teams, and the other half were frontline staff members. No physicians were interviewed, as they rarely enter data. All but one of the informants were women. Informants' experience with CR and working with the registry varied greatly (**Table 2**). The interviews were conducted in Denmark and England during the period September 2016-April 2017 and lasted between 15 and 47 minutes.

Table 2. English and Danish informants' experience of working with cardiac rehabilitation and with the NACR and DHRD registries, respectively			
	English informants	Danish informants	
Experience with cardiac rehabilitation	<1 to 23 years	2-30 years	
	(median 15 years)	(median 10 years)	
Experience working with the registry (NACR in	2 months – 10 years (median	6 months - 3 years	
England; DHRD in Denmark)	8 years)*	(median 1 year)**	
* = Maximum possible time for NACR is 10 years	** = Maxium possible for DHRD is 3 years		

Struggling with practices

One theme and five categories, each covering three subcategories, emerged from the analysis (**Figure 1**). Representing the latent interview content [31], the theme 'Struggling with practices' concerns the multi-facetted challenges that may be part of adopting the CQR. It suggests that implementation of a CR registry is not a simple task of merely entering data into a reporting system, but rather a complex process that requires changes in practices and mindsets, as well as a sustained dedicated effort. This may be challenging in an everyday practice already faced with high workloads and competing changes to be made. Furthermore, the theme represents a more

subtle struggle of getting acknowledgement for CR as an important part of cardiovascular treatment.

The categories underlying this theme reflect factors that the informants experience influencing the implementation and use of the CQR.

Figure 1: Theme, categories and subcategories in the study.



The data entry process

This category covered the informants' perceptions of organization of data entry processes and fitting it into everyday practice.

The implementation of the British registry (NACR) and the Danish registry (DHRD) had not received much attention, and some described using the registry as a "small thing". Implementation efforts were found to be locally organized and clearly focused on getting access to the web-based system, data collection and data entry. Roles and responsibilities were allocated naturally, in many cases without formal appointment by management. Either the most interested staff members took on a leading or coordinating role themselves, or taking the lead was part of the expectations of being the local CR coordinator. Some Danish informants found that lack of management interference and lack of coordination within the team made implementation an individual responsibility. Most teams had found it "natural" that the

clinician seeing the patient – thus collecting the data – also was to enter data. Some perceived it important to have clinical expertise to manage the task properly. However, at a few sites, both in England and in Denmark, the task of entering data was passed on to administrative data entry staff, or to a few of the clinicians instead of all team members. The aim was to save precious clinician time, and to specialize and divide work tasks (administrative versus clinical).

In both countries, collecting and entering data was an extra workload that was to be fitted into everyday practice. The nurses, who collect and enter the majority of the data, found this more or less time-consuming and some perceived it as a cumbersome task. The physiotherapists and dietitian on the other hand, who have less extensive data forms to fill out, perceived data entry as rather quick and straightforward. Regardless of professional role, most found it necessary to register data onto paper-based records first as focusing on the computer screen while the patient is present would disturb patient contact. Only at one English site, direct online entry without intermediate paper records was reported, but it still took place after the patient visit. Furthermore, locally or individually invented notes/lists were used to keep track of patient follow-ups at almost all sites. The informants found this necessary because the registries were not designed to flag patients due to specific follow-ups, although such data may be required by the registries.

The informants found it – often an experience gained along the way – as a clear facilitating aspect to make data entry part of everyday workflow and enter the data immediately after the patient visit, or at least the same day. By doing this, data are fresh in memory, and the task seems more relevant.

What I think has worked well is that [data entry] has been tied to existing routines. Because it... makes you remember it much easier. And I also believe that 's why we get so many patients entered, as we do. It 's tied up to existing routines. (DK8)

Some sites reported struggling with getting data entered. Here, the data collection and/or online data entry was not an integrated part of daily work processes, but rather a duty

performed when time permitted or when extra resources were allocated, for instance before the annual reporting deadline to the registry. This was described as a very time consuming and negatively associated task.

The task of collecting data may require redesign of practice in order to be able to fill out the registry's minimum requirements, for instance introduction of new routines such as weighing the patients or screening for depression using a recommended screening instrument. Furthermore, collecting patient-reported data by questionnaires and keeping track of follow-ups require attention and new routines. Both data collection and -entry necessitate collaboration and division of tasks within the multidisciplinary team. Some informants found that data collection structured the conversation with the patient, whereas others did not find any positive influence on daily routines.

Resources and management support

This category included issues related to resources and prioritization, support from management, and support within and external of the CR team.

Although working with the registries was described as more or less time-consuming, only few English and Danish sites had received extra resources for the task. Time must thus be found elsewhere, mostly reported taken from the dedicated patient time. Another solution was to register only the minimum required variables, although some found this unsatisfactory, as they believed output data would be more interesting if most/all fields were filled out. Nonetheless, most sites in both countries prioritized the task of collecting and entering data highly, either because they supported the idea of a registry and wished to contribute, or because reporting was mandatory (Denmark). A few informants did report low priority of the task, even in Denmark despite the fact that reporting is mandatory. This was mainly because of low staffing or because the registry got a back-seat to other high priority activities. Some of the informants felt bad about this as they knew it was a "must-do task" which they dutifully wished to fulfil. Nearly all informants reported low levels of knowledge, interest and support from management in the initial phases of registry implementation, where data was collected and entered. A "silent accept" was experienced in several sites in England where the uptake of the registry was bottom-up driven by engaged clinicians, and management for instance allowed staff to attend training. While some reported that this lack of interest remained even when feedback data started coming and results were getting published, others experienced that the management were very interested in data and results.

I met a lot of resistance from my manager who said we are spending clinical time inputting and gathering data but we're getting no feedback. [...] And now that manager has changed her mind about the value of NACR and thinks that the information is brilliant, because now the commissioners want to use it as their reporting tool. (UK7)

In England, most of the staff involved in the registry in its early years had received formal training under the auspices of the registry administration. The new users had on the other hand not had training, and relied on written guidance, or if applicable, colleagues. In Denmark, in contrast, no formal training had been offered at any time, although some of the coordinators had participated in start-up meetings. As the DHRD was relatively new, most of the informants also had had no colleagues to teach them about the system, which meant that they had to learn the system by themselves as they went.

And it was learning by doing, and that's the way it was. [...] I have not been introduced to anything what so ever, so it's jumping right into it, and find out what we are supposed to inform about, and what we are not to inform about, and what we are supposed to write, what we are not supposed to do, and... Well. (DK9)

In England, the users experienced very good help from the national administration office, although some of the most recent new users did not know of the support opportunities. This lack of awareness was also seen among some of the Danish informants, who did not know of any external support opportunities, and therefore relied on colleagues or merely resigned

receiving help. Of those who did know whom to contact for help, experiences were mixed, and in particular, a lack of action on functional problems in the registry was reported. Among the very few who had insight into the registry organization system, this was explained as inertia within the system. The lack of action was discouraging.

Use of formal and/or informal networks was common among the more experienced staff, both for asking questions and for discussions. The more inexperienced staff did not have this opportunity, however, as formal networking opportunities were rarely offered to them, and as new in the field they had no informal networks in the CR community.

Communication from national administration offices to users about the registries was perceived a problem both Denmark and England, however rarely in the latter. This meant that important information may not reach the relevant users; for instance, the physiotherapists at one Danish site had not received information about re-launch of the registry and thus had not entered any data even after one year, and annual reports did not reach the clinical staff.

Registry quality

This category covers structure and technical quality of the registries, and the relevance and reliability of data.

The structure and technical quality of the registries was important for their usability. Most found it easy to enter and navigate both the NACR and the DHRD, and the English informants described that the user-friendliness of the NACR had improved a lot over the years. However, meanings were divided both within and across countries concerning the registry structures, where some perceived it fairly adapted to the patient pathway, while others found it challenging to enter the relevant data due to the perceived mismatch. In DHRD, data linkage to external registries had been established to save time in data collection and entry. However, due to delays in the external registries and technical problems, the users experienced missing data and

problems with the quality of data pulled into the DHRD, which was a source of remarkable frustration.

What I think more about is that is it poor data catchment. Really poor. There are many things it doesn't capture; medicine, diagnoses... So there are things it catches where you go 'What? That's not true'. Everyone actually thinks it's a little annoying to look at something which isn't correct [but we have been told by management not to correct this, as it is not marked as mandatory variables]. And you'd think, what can they use this for? If data are not correct or even missing? And I think we use a great deal of energy on speculating about... is it wasted resources, this, or what is it supposed to be used for? I think this is most frustrating. Yes, it is... (DK9)

Timesaving functions in the registries, e.g. body mass index calculators or the possibility to copy a summary of data into the electronic health record, were on the other hand highly appreciated and encouraged use of the registry.

The perceived relevance and reliability of data were reported important for the motivation to use the registries. The informants found the chosen variables relevant. However, they did not cover *all* the important aspects of CR, and most would like the variables (which are process and clinical outcome measures) to be supplemented by variables that capture psychosocial values, as this was expressed as important outcomes when working with CR. The English informants appreciated the possibility to adapt the choice of variables to match local practice, as only few variables were mandatory. However, some found it necessary to supplement the NACR with local databases, as those were easier to fit with local demands for data.

In both countries, but particularly in Denmark, users experienced ambiguity in the variables. This caused frustration in the data entry phase, and in addition, a pronounced distrust in data especially among the Danish informants.

Some of it is open to interpretation and sometimes I have scratched my head and 'does it mean this or does it mean that' and I've input it one way and colleagues may have put it differently (UK5)

... the data that are being entered, you can write anything. And it is totally dependent on how you... view it yourself. So I don't think it is [...] valid. [...] You can't use it for anything at all. So I actually think it is [...] a little demotivating. (DK12)

Quality improvement

In this category, we included both beliefs and actual experiences of the usefulness of registries for quality improvement.

Insight in feedback data was found to vary greatly, both within an in between the two studied registries. In England, where feedback data had been published for years, most informants had at least had a glance at feedback data, and some knew data well. In contrast, most Danish informants had neither received nor sought feedback data from the relatively new DHRD. Some had studied data, although it was found to be partly difficult to understand.

The actual *use* of data varied. English coordinators used data to provide productivity data to local commissioners, and a few (primarily English) had used the data to put pressure on their management to invest more in CR and found this very useful. In general, there was limited awareness of the fact that data were gathered to aid local quality improvement. Rather, it was believed to be used for research. Some knew data were supposed to be used for local quality improvement but realized that this requires time and competences and that neither are present in most CR departments.

If data is to be useful, it needs to be reviewed, discussed, and outcomes need to be considered in relation to own practice. When short staffed, this type of work does not get done. Our Heart Failure colleagues have used our data to present the numbers of heart failure patients being offered Cardiac Rehabilitation. But from the management of our service, we have not yet really used NACR to change practice. (UK11)

Some stated that quality improvement takes place anyway, but not based on registry data. Among English informants, some described to be motivated to use NACR by seeing improvements in the registry data. There were however staff in both countries who did not find the database useful at all. In particular, some of the Danish informants were highly sceptical of using data, as they had a great distrust in its validity. Following this, they regarded the resources spent on data collection and entry as a waste of time.

Informants in both countries supported the *idea* of a registry as this meant a possibility to improve quality of CR for the benefit of the patients. It was also believed to be an opportunity for acknowledgement of CR in a wider sense, and to highlight the extent and importance of the work that staff put into daily practice.

...everyone needs an audit wherever you are, there has to be something to acknowledge how many patients coming in, why and how it's working, so we knew there had to be audit. (UK12)

Some informants, both in England and in Denmark, valued the possibility to compare results of their own department to others, and stated that this could potentially provide learning opportunities. Others did not appreciate the benchmarking, as it added a competitive element.

The wider health care context

This category covers issues of the context, meaning the organizational and wider environmental factors that may affect implementation. It includes the patient, CR as a clinical field, and the wider healthcare context.

The patient was clearly at the centre of attention among the interviewed clinicians. The use of a registry sometimes supports this focus, for example the abovementioned structuring of the conversation with the patient and the prospect of receiving acknowledgement for CR. Others described the registry as a disturbing element, forcing them to use precious clinical time on data entry instead of on the patient. As patients are individuals, their pathways sometimes

diverge from the norm and were thus difficult to fit into the registry, and patients may not wish to respond to questionnaires required to fill out the registry. As a clinician, one may have to choose between spending time on issues that are relevant to the individual patient versus working through all variables necessary to fill out the registry.

Both the English and the Danish informants found themselves faced by growing administrative workloads in general, making it even more difficult to find time for the registries. A few of both the English and Danish clinicians expressed healthcare as increasingly being a business driven model, where the registries and the focus on documentation and reporting was an integrated part. For some this was already the new reality, others realized that they would have to adapt.

You just take it as part of the workload, it's what you do. Audit and information gathering now is routine in health care and it's right. (UK8)

In the heart failure clinic, registering data has been part of the job for years. But it isn't for cardiac rehab nurses. Therefore, it's another culture, that one is... that it is part of the job to enter data into a registry. (DK6)

Yet others did not express awareness of culture issues and were in general opposed to the increased documentation.

Among the Danish nurses, some expressed fear of their professionalism being set aside, as they believed management focused too heavily on following registry requirements instead of clinical experience.

Some of the English nurses compared the NACR to other cardiac CQRs with economic incentives for participating, noting that this seemed to make a difference for prioritization at management level. The fact that participating in NACR recently had become part of a certification programme for CR had gained interest among some commissioners. In Denmark, the informants were generally unaware of laws or national guidance that mandated or recommended data reporting, but did know that data reporting was non-optional.

DISCUSSION

This study of real-life implementation experiences among professionals taking active part in registry usage documented a range of experiences and beliefs. Many were found to be similar across England and Denmark, but there were also a number of differences both within and between countries. Although these experiences and perceptions were not always explicitly expressed as barriers and facilitators for implementation, they may to some degree of certainty be interpreted as such. In the following, we thus highlight and discuss some of the key findings while assessing them as barriers and facilitators for implementation (for an overview, see **Table 3**). Since many of our findings can be related to the Consolidated Framework for Implementation Research (CFIR) [33], which identifies a number of determinants of implementation divided into five domains, we let the CFIR domains provide a structure for the discussion.

Table 3. Selected key findings assessed as barriers and facilitators for clinical quality registry
implementation, organized by domains in the Consolidated Framework for Implementation
Research (CFIR)

CFIR domain	Barriers	Facilitators
Intervention characteristics	Practice changes often required but not foreseen. Ambiguity of registry variables. Poor registry design/functioning with regards to e.g. patient follow-ups. Poorly functioning data linkage. Typing on computer screen diverts attention from patient.	Continuous development and adjustment of registry function and content, as needed. User-friendly layout and design.
Inner setting & Outer setting	Lack of management support in data collection and entry phase.	Management interest in output data (results).
	Lack of incentives.	Feedback data regarding local use of resources and local quality.
		Use of registry included in cardiac rehabilitation certification programme.
		Mandated participation in registry.
		Results part of national quality indicators.
		The prospect of improving patient care and raising acknowledgement for cardiac rehabilitation.
		A culture of data reporting.
Process	Lack of formal planning of implementation process.	Training and support of users.
	Implementation a responsibility of the individual clinician (or few clinicians).	
	Lack of support and clarification.	
Characteristics of individuals	Lack of knowledge about purpose of the registry.	Local registry advocates/ champions.
	Lack of know-how and resources to use data for local quality improvement.	

The CFIR domain *Intervention characteristics* emphasizes the necessity of adapting a new intervention to the setting, except for its core components, which are essential and indispensable elements of the intervention [33]. Our finding that data *collection* require redesign of practice at some sites, primarily Danish sites because of the larger number of mandatory fields, is therefore interesting because it indicates that not only is use of the registry to be fitted into practice, practice processes are also influenced by the registry. This may be a positive effect if it contributes to improving quality or limiting unwanted variations in the provision of care, but seen from an implementation perspective, it adds to the complexity. Most informants did not seem to be aware of the necessity of these practice changes until being in the

process of implementation. These aspects highlight that registry implementation is more than merely registering data into a database and hence, a more complex task than apparently first expected. To our knowledge, this aspect has not previously been described in CQR implementation. Previous research underscores that foreseeing necessary practice changes and including them into an implementation plan contribute to successful implementation [37].

Another aspect of the intervention characteristics domain in CFIR is the 'design and quality' of the registries, and in our study, three main issues emerged. Firstly, the ambiguity of variables was a source of frustration, and both real and perceived effects on data quality is to be taken seriously, as it affects users' motivation to enter data, and because high data quality is fundamental for the use of data for quality improvement and research. Secondly, the fact that all informants but two reported using locally invented registration forms/lists to keep track of data and patients and to retain focus during the patient encounter indicate that there is room for improvement of the registries' user-friendliness to better fit multiple different practice processes, and thus facilitate registry use [1, 4]. This need is underscored by the finding that use of paper-based data collection may introduce opportunity for data error in the transfer to the web-based platforms [38]. The third aspect of design and quality is data linkage, which has often been emphasized as a great advantage of CQRs, saving precious clinical time by avoiding double entry and improving data quality [4]. Although data linkage was supposed to be a facilitator for registry use in the Danish registry, the poor execution seem to have had the opposite effect; to a high degree creating a barrier because of the frustrations and demotivation it caused. This emphasizes the importance of assessing the quality of the source registry and thorough testing before data linkage is implemented [4]. Altogether, the issues related to 'design and quality' stresses the need for registry organizations to secure sufficient resources to continuously react on and remedy flaws, since such agility appears to facilitate continuous support of a registry.

The next two CFIR domains are *inner and outer setting* [33], which deal with structural, economic, political and cultural contexts in which the implementation takes place. In line with CFIR suggestions, we regard the lack of management support in the data collection and entry phase as a major barrier for implementation. In addition to the immediate challenge of not prioritizing and allocating necessary resources, it may also indirectly affect the implementation climate because of the lack of active interest [33]. In contrast to the lack of interest and support in the data entry phase, the managerial interest in output data spurred data entry, which mirrors previous Swedish findings [9]. It was beyond the scope of this study to examine managers' perceptions of CQR implementation, but our findings point to that this may be an important focus for further study.

'Incentives' are another part of the settings domains in CFIR, which seemed to play an important facilitating role in our study. In England, receiving feedback reflecting local quality of care and use of resources emerged as an incentive to voluntary join NACR in its first years, and although still important, now seem to be co-working with another incentive: certification, to encourage participation in the registry. In Denmark, the external policy incentive of mandatory participation did not guarantee full data entry, as there were reports of differences in local prioritization, reflected by coverage data in the DHRD annual report [39] and also mirrored in Swedish findings [11]. Although our study may provide some explanations, not least the overall limited focus on securing implementation, it could be a combination with a lack of penalties/incentives on a national level. Notably, a new external incentive was introduced in 2016 as results from CQRs were included as a major national and local healthcare quality indicator [40], and this is likely a reason for the Danish informants' reports of managements' interest in performance data. However, based on our data, it seems that there is an imbalance between the strong focus on output data and the relatively little focus on the processes of collecting and entering data and using it for local quality improvement. Moreover, although incentives related to audit and feedback, national legislation, and programme certification or other reimbursements have been suggested to be more effective than voluntary participation

[10, 41], improving patient care and raising acknowledgement for CR emerged a less tangible but strong incentive. This drive could explain some of the within country differences in participation, and could possibly be activated more explicitly as a strategy to improve participation.

The informants' expectations that documentation per se will lead to acknowledgement of CR is mirrored in a recent report by the World Health Organization, where use of national audits to document provision, quality and outcome of rehabilitation services is suggested to raise awareness among for instance policy makers [42]. In a wider perspective, the motivation to document data in a registry reported by our informants seem to be reflecting an institutionalization of CQRs [43], as part of the quality measurement enterprise permeating healthcare [44]. These expressions about a culture of data reporting may be important in an CQR implementation perspective, as it – as suggested by e.g. CFIR – can explain why efforts that are targeted at more tangible aspects fail to work, and in the cases of the present study can provide an additional explanation to within-country differences in implementation experiences.

The last two CFIR domains are *individuals* and the *implementation process*. Individuals are those who are involved in the intervention and/or the implementation process, which in turn is the active change processes aimed to achieve use of the intervention [33]. In our study, these two domains were closely related. Very little formal planning of the implementation was reported in either of the studied countries, which, combined with the lack of management involvement, made implementation a responsibility of the team or even individual staff members. In this situation, the capacity of highly engaged teams or individuals played a vital role in facilitating the implementation. The important role of such champions has been emphasized in numerous implementation frameworks, including CFIR.

Besides engaged individuals and teams, the training and support by the NACR registry administration clearly facilitated data entry, whereas the lack of training and lower level of support experienced among DHRD users in Denmark interestingly did not seem as a distinct

barrier for getting data entered. This points back to context, as it is likely to be an effect of the mandatory participation. In addition, it could be indicating that the computer literacy in general is high and that the system has a user-friendly design, which has previously been indicated as facilitating implementation [1]. While some may argue that this suggests that training and support is not necessary as part of CQR implementation, the findings must be seen in perspective of the issues with data quality that became evident in later stages of registry use, when the users – along the way – found out that there is ambiguity in some registry variables and that they may be filling things out incorrectly. Here, lack of support and clarification was a barrier, annoying users. This, in turn, affected the perceived trustworthiness of the registries and demotivated the users. Although a few NACR users mentioned issues with data, this problem was not prominent in England, suggesting that the decade long continuous development of the registry and high support level is making a difference. Some of the differences we found between NACR and DHRD are thus likely to be due to registry maturity and administrative resources.

Besides data entry issues, not all informants were aware of the purpose of the registries, and/or were lacking resources and know-how to use data, and overall, very few of our informants reported examples of actual use of data to improve care. Ensuring adequate resources and competencies of the staff has been emphasized both to ensure high-quality registry data [1, 38] and use of data for quality improvement [9], and this focus should be continuous to take into account e.g. well-trained staff that leave and new staff that should be trained [12, 38]. However, it is evident that front-line staff and managers cannot stand alone; all stakeholders have important roles to play in order to secure successful use of the registries [33, 45].

Overall, the many similar experiences among users of the two CQRs suggest that there are some common barriers and facilitators of using a CQR for CR. They may be common for two reasons: firstly, because they may be generic to implementation [29], as indicated by their presence in compilations of previous implementation studies such as the CFIR. Secondly, it indicates that

there may be aspects of using CR CQRs that are specifically tied to this quality improvement tool per se [4, 29], and therefore present across settings. The dissimilarities on the other hand seem to be explained in part by differences in registry administration, design, and incentives. The relative maturity of NACR compared to DHRD creates different challenges and opportunities for users and administrators, as different implementation phases require different considerations [12]. The dissimilarities were furthermore interpreted as reflecting differences in local and nationwide healthcare organizations and culture, and individual characteristics of informants.

Strengths and limitations

We consider the design with two international cases a real strength, adding valuable insights beyond the single registry and widening our understanding of potentially important factors to consider in similar implementation situations [46]. To further enhance trustworthiness, we strived to include informants with different roles and experiences to give a broad perspective on possible barriers and facilitators for implementation [47], and kept on until we got no new information from the interviews [48]. In spite of our efforts, there may be experiences that were not covered, and the questions may have focused on certain aspects while leaving out other possibly important aspects. Use of broad and open ended questions were intended to minimize this restraint on subjects [28]. Nevertheless, qualitative findings are by their nature context and case dependent [49], and transferability to other settings should be judged by the reader [31].

Researcher preconceptions may influence both the data collection and analysis, and is therefore important to describe. The primary investigator had an a priori expectation that implementation of the registries often would not receive much focused attention and that it would be challenging for staff to manage in a busy everyday practice, resulting in poorly implemented registries. To limit influence of such preconceptions, we used researcher triangulation [49], where the two co-analysts had other backgrounds and thus analysed data from different perspectives. This promoted valuable discussions between the co-investigators

that we believe strengthened our insight and thus our categorization of data, hence enhancing the quality of the analysis [31, 49].

Because we included two countries in this study, interviews were carried out in two languages, where English is second language for both interviewers. Despite a good knowledge of English, there may be things that we did not understand as subtle as we did with the Danish interviews, limiting e.g. the flexibility to follow up on unexpected information during the interviews. To remedy possible limitations in our understanding of the oral language, transcriptions were carried out by experienced native English transcribers with a good knowledge of the English healthcare system and clinical registries, and they were also asked to clarify the meaning of a few idiomatic expressions [50].

CONCLUSION

This two-country, real-life study points to a range of factors that may support or hinder the implementation of a CQR for CR according to the healthcare professionals ' perspectives. Implementation can be a more complex process than first expected and staff may experience a struggle of fitting use of the registry into a busy and complex everyday practice, often with little support from management. The findings are relevant, because they emphasize that a registry is not implemented by merely launching it, and that getting high-quality data into a registry requires a dedicated, sustained effort that involves not only staff but all stakeholders. The study thus highlights the importance of acknowledging the challenges of CQR implementation and of supporting it by applying appropriate, if necessary multi-facetted, strategies at multiple levels. Results may be important to consider for all stakeholders involved in planning, launching or implementing a new CQR for CR or in related clinical fields, or for those involved in improving use of an existing registry.

LIST OF ABBREVIATIONS

CQR: Clinical Quality Registry CR: Cardiac Rehabilitation DHRD: the Danish Cardiac Rehabilitation Database NACR: the National Audit of Cardiac Rehabilitation (UK) CFIR: the Consolidated Framework for Implementation Research

DECLARATIONS

- Ethics approval and consent to participate: The study was approved by The Danish Data Protection Agency, REG-149-2015. No ethical approval was necessary according to laws, since it is not a biomedical study with inclusion of human material (Denmark), and did not include patients (the UK). All informants gave oral and written informed consent prior to onset of the interviews, including permission to audio record the interview. Data were treated confidentially.
- Consent for publication: Not applicable
- Availability of data and material Data used during the current study are available from the corresponding author on reasonable request. Parts may be omitted to ensure confidentiality of informants.
- Competing interests: CLE is functioning as a secretary for the chair of the Danish Cardiac Rehabilitation Database steering committee. The study was independent, conducted apart from this role. CH is a board member of the steering committee for the Danish Cardiac Rehabilitation Database. PD is the Director of the National Audit for Cardiac Rehabilitation, UK. ADZ is the Chair of the steering committee for the Danish Cardiac Rehabilitation Database. PN and GB No competing interests.
- Funding: The study was funded by the Department of Medicine, Holbaek University Hospital; The Danish Knowledge Centre for Rehabilitation and Palliative Care, University of Southern Denmark and Odense University Hospital, Southern Region of Denmark; and the Region Zealand Health Scientific Research Foundation. The funding bodies had no role in the design of the study, in the collection, analysis, and interpretation of data or in writing the manuscript.
- Authors' contributions: All authors contributed to the design of the study. CLE, CH and GB developed the interview guides, CLE and CH performed the interviews, and CLE, CH and GB performed the analysis, with the other authors being critical peers. CLE drafted the manuscript with intellectual contribution of all co-authors. All authors read and approved the final manuscript.
- Acknowledgements: We give our sincere thanks to all the informants in both Denmark and England for taking their time to participate in the study. Thank you to the staff in the NACR administration team for valuable help and efforts in preparing the study and data collection.

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Additional file 1: Interview guide, English version

Briefing / introduction	Information (bullets)
Presentation of	Who are we
interviewers and purpose	Purpose
of the interview	Roles
Frame of the interview	Our focus is the implementation of DHRD/NACR. We define implementation as <i>the planned and systematic introduction of</i> <i>the database, with the aim to integrate the use of it in daily</i> <i>practice</i> Timeframe Recording Confidentiality/anonymizing Clarification of questions
Informed consent	
Presentation of informant:	
Background	What is your professional background and what is your role in
Role concerning NACR	relation to implementation of NACR?
	 How did you get this role?

Implementing the database in your department	Interview questions		
a) Procedures / what happened	Tell us about your department's implementation of NACR (<i>probes</i> : who, when, what did you and your colleagues do? Why?)		
	 Please describe what worked well –and why/what made it work well/ facilitated the process? What worked less well? Why / what made it work less well /acted as a barrier in the process? 		
	 Could you briefly describe the model (process) you have chosen for entering data into the database? Why did you decide – or end up – doing it this way? To what degree does use of the database give you an extra work-load? 		
	Which factors influenced the decision to implement NACR in your department?		
b) Division of work and cooperation	 Who was / is formally appointed with responsibility for implementing/sustain use of the NACR as coordinator, project manager, team leader, or other similar role? Has someone (or a team) outside your organization been helping you with implementing NACR? 		

c) Support and interest from management	To what extent do you network with other health professionals outside your setting regarding NACR? Has anything been done to encourage individuals to commit to use the database? - Has this been successful? What level of support have you experienced from leaders at your department/ hospital?
	Have your department set goals related to the implementation of the database? - Are these goals monitored for progress?
d) Organizational activities / support	Now I would like you to think about the organization of the work using the NACR, for instance division of work, planning the data entry process, follow-up on results. What possibilities are there to get support to the process of using the database? What kind of support is available to help you use the database? E.g. online resources, toolkit, "help-desk"/ administrations office, training/courses and the like - Is it unambiguous what to register?
Feedback from NACR	
e) Received feedback	Do you receive feedback reports about the implementation or the intervention itself? Apart from the annual report, do you receive any other kind of feedback? Oral or written. (From network, external partners, leaders, patients, colleagues)
f) Use of feedback	 How – or in what ways – do you / your department use the feedback you receive? Did your colleagues receive the same feedback / have they seen it? If they use feedback: Who is working with the feedback? If they use feedback: To what degree do you experience support from you colleagues in the improvement work? Does the annual report or other feedback help you assess progress towards implementation or treatment targets? What is your perception of the feedback you or your department get? Quality Relevance Wishes for future feedback

g) Feedback strategy	What do you think of data from your local department will be published openly?
Importance of the datab	ase for daily clinical work
h) Other projects and activities	To what extent might the implementation of the database take a backseat to other high-priority initiatives going on?
i) Relevance for clinical practice	Which effect has NACR had on daily practice?
	What is your opinion of the indicators that are chosen for NACR?
	In what ways do you think the NACR will affect cardiac rehab in the future?
	Overall – do you believe the database is optimizing cardiac rehab for the benefit of cardiac patients?
j) Overall benefit	Overall, do you think the work with NACR is worth the effort?
Debriefing / end of interview	
Wrapping up	We are about to be finished with the interview Is there anything else you would like to tell us / anything to add?
what will happen now	May we contact you again if we have any additional questions / details?
	Information about writing of paper and publication

Additional file 2: Example illustrating the coding process of content analysis

Examples from three different English interviews.

Text unit from transcribed interview	Code	Subcategory	Category
Interviewee: I [asked a colleague] the other day when I had to put in the initial contact data, I needed to refer to the administrator and a colleague of mine, the Band 7 nurse she was able to give me more information about what needed to be filled in because I didn't know, like the GP address and whatever, the patient address and all that business.	Internal support	Internal and external support	Resources and management support
Interviewer: What kind of support is available to help you use the database? Interviewee: Just speaking to colleagues really. I'm not aware of any other resources or anything like that.	No knowledge of external support	Internal and external support	Resources and management support
Interviewer: To what extent might the inputting of data into the database take a back seat to other high priority tasks? Interviewee: It doesn't. I see the patient, I enter the data and that's it. It's done straight away []	Data entry part of routine	Work processes	The data entry process
[] over the last couple of weeks we've been a bit quieter than we normally would be, so I've had the time [to enter data].	Enters data when time left	Work processes	The data entry process
Interviewer: Have you ever considered that the nurses would do the registering? Interviewee: We just don't have time. When we originally started we were doing more of it and we did consider should we be inputting the data [] it was basically a time thing because [our admin staff] does X hours a week with us and we don't have to think about that and we can concentrate on what we do and all the patient stuff, erm, so yes it was originally considered and it was decided that it wasn't appropriate for us to do other data inputting. It wasn't a good use of our time and sort of expertise []	Work division nurses vs. admin staff	Roles	The data entry process

Paper III

Facilitators for using data from a quality registry in local quality improvement work – a survey study on cardiac rehabilitation

Authors:

Cecilie Lindström Egholm^{1,2}, Charlotte Helmark³, Jan Christensen^{2,4}, Ann Catrine Eldh ^{5, 6}, Ulrika Winblad⁶, Gitte Bunkenborg⁷, Ann-Dorthe Zwisler², Per Nilsen⁵

Affiliations:

- 1. Department of Medicine, Holbaek University Hospital, Region Zealand, Denmark
- The Danish Knowledge Centre of Rehabilitation and Palliative Care, University of Southern Denmark and Odense University Hospital, Odense, Denmark
- 3. Department of Cardiology, Zealand University Hospital, Roskilde, Denmark
- Department of Occupational- and Physiotherapy, Copenhagen University Hospital, Rigshospitalet, Copenhagen, Denmark.
- 5. Department of Medical and Health Sciences, Linköping University, Linköping, Sweden
- 6. Department of Public Health and Caring Sciences, Uppsala University, Uppsala, Sweden
- 7. Department of Anesthesiology, Holbaek University Hospital, Region Zealand, Denmark

Contact author:

Cecilie Lindström Egholm, PhD student, Master of Science of Public Health, Department of Medicine, Holbaek University Hospital, Smedelundsgade 60, 4300 Holbaek, Denmark; and the Danish Knowledge Centre of Rehabilitation and Palliative Care, University of Southern Denmark and Odense University Hospital. E-mail: ance@regionsjaelland.dk, phone: +45 2497 5436

Keywords:

Cardiac rehabilitation; Clinical quality registries; Continuous Quality Improvement; Audit and feedback

Word Count:

Abstract: 272

ABSTRACT

Objectives: To investigate use of data from a clinical quality registry for cardiac rehabilitation in Denmark, considering the extent to which data are used for local quality improvement and what facilitates the use of these data, with a particular focus on whether there are differences between frontline staff and managers.

Design: Cross-sectional nationwide survey study.

Setting, methods and participants: A previously validated, Swedish questionnaire regarding use of data from clinical quality registries was translated and e-mailed to frontline staff, mid-level managers and heads of departments (N=175) in all 30 hospital departments participating in the Danish Cardiac Rehabilitation Database. Data were analysed descriptively and through multiple linear regression.

Results: Survey response rate was 58% (101/175). Reports of registry use at department level (measured through an index comprising 7 items; score min 0, max 7) varied significantly between groups of respondents: frontline staff mean score 1.3 (SD=2.0), mid-level management mean 2.4 (SD=2.3), and heads of departments mean 3.0 (SD=2.5), p=0.006. Overall, department level use of data was positively associated with higher perceived data quality and usefulness (regression coeff. 0.22, p=0.019), management request for data (coeff. 0.40, p=0.008) and personal motivation of the respondent (coeff. 1.63, p<0.001). Among managers, use of registry data was associated with data quality and usefulness (coeff. 0.43, p=0.027), and among frontline staff, reported data use was associated with management involvement in quality improvement work (coeff. 0.90, p=0.017) and personal motivation (coeff. 1.66, p<0.001).

Conclusions: The findings suggest relatively sparse use of data in local quality improvement work. A complex interplay of factors seem to be associated with data use with varying aspects being of importance for frontline staff and managers.

INTRODUCTION

The use of clinical quality registries (CQRs) is frequently emphasized as a means for continuous quality improvement [1,2]. By collating standardized information on clinical care processes and patient outcomes within demarcated areas of healthcare and making feedback data available to the participating sites, the use of CQRs can provide the basis for improving suboptimal practice [3].

However, to achieve the purpose of quality improvement, the use of CQRs must be thoroughly implemented, including active use of the collected data for follow-up and learning opportunities. Studies indicate that this may often not be the case. A recent systematic review found that only a few high quality studies have been able to show an effect in terms of improved quality of care [4]. Despite substantial investments into increased use of CQR data in Sweden, national evaluations have shown that the registries have not been drivers of local quality improvement, with data use often being limited [5]. On the other hand, the application of data in local quality improvement work may differ between registries [5,6], indicating data use may be registry and context-dependent.

Some of the determinants for use of data include: data relevance [7,8], perceived quality of data, timeliness of feedback [9], know-how among staff [10], sufficient resources [5,10], collaboration between relevant organizational tiers [6,7,11], and engagement of both frontline staff and managers [12]. Thus, while collaboration and engagement across the organization is important, it is unknown whether staff and managers are influenced by the same determinants, and whether they share perceptions on the use of CQR data. Studies of other types of quality improvement initiatives have suggested that determinants for use of data may differ between these two occupational groups, and that managers may have more overall positive views of the initiatives compared to frontline staff [13–15]. As such disparities have possible implications for the use of data [12,13], studies in the field of CQRs seem warranted.

CQRs are typically introduced in clinical areas where there is a gap between evidence and practice [3]. One such area is cardiac rehabilitation, which despite being an important part of secondary prevention for patients recovering from heart disease [16], is consistently reported to have evidence-practice gaps [17,18]. CQRs with the purpose of monitoring and improving cardiac rehabilitation services have been established in at least seven countries [19]. Although sizeable resources are invested into development, administration and data collection of these CQRs [3,19], it remains unclear to what extent the data are being used and what drives the use of data for local quality improvement among registries in this clinical area. The need for knowledge on these aspects is underscored by the fact that data-driven quality improvement currently is high on the healthcare agenda, with CQRs potentially having significant roles in delivering data [2,20,21].

The objective of this study was to investigate the use of data from a CQR for cardiac rehabilitation in Denmark, considering the extent to which data are used for local quality improvement and what facilitates the use of these data, with a particular focus on whether there are differences between frontline staff and managers. The CQR in question represents a nationwide registry based on international evidence, intended to be used primarily for quality improvement [22].

METHODS

Study design

This cross-sectional study used a nationwide survey questionnaire provided to frontline staff and managers who work with cardiac rehabilitation and report data to The Danish Cardiac Rehabilitation Database.
The Danish Cardiac Rehabilitation Database

The Danish Cardiac Rehabilitation Database has been operating since 2015 and is based on clinical guideline recommendations [22]. Participation is mandatory for all departments delivering phase II (post-discharge) cardiac rehabilitation [22,23]. Implementation and use of the database is a local responsibility, with possibility to obtain support from a database quality manager at The Danish Clinical Registries, from quality registry coordinators in the healthcare region, or from local quality improvement units. Data collection is a combination of manually entered data (a task performed by clinicians and/or medical secretaries) and automated datacapture from patient administrative systems [22]. Results on 13 selected process- and outcome indicators are available through regional web-based information systems (updated monthly) and through annual reports, which are displayed publicly. Data are reported on a local, regional and national level and presented according to standards, for the opportunity of benchmarking and intra- and inter-site learning.

Nationwide survey

For the purpose of this study, we applied a generic survey questionnaire, the Quality improvement While Adopting Quality register outcomes survey (QWAQ). QWAQ intends to measure a range of aspects that may facilitate use of CQR data for quality improvement work, and consists of 50 items regarding quality of clinical care, quality of registry data, organizational conditions for registry work, and use of data for quality improvement [12]. All items are scored on four or five-point Likert scales, and form six indexes covering: "The healthcare unit's use of registry data" (7 items); "Data quality and Usefulness" (5 items); "Support from outer setting" (3 items); "Resources" (4 items); "Management request for registry data" (4 items); and "Management involvement in registry-based quality improvement" (2 items). The remaining 25 items are independent. The formation of the indexes was based on theoretical assumptions from the field of quality improvement and implementation, empirical knowledge from the original developers' work, as well as factor analysis [12].

145

QWAQ, which was developed in Sweden, was translated and cross-culturally adapted into Danish using widely recognized methodology [24]. The pre-final Danish version was pilottested for acceptability, clarity and cultural applicability through cognitive interviews among registry users (n=15) representing different groups of staff (e.g. frontline staff, managers) with different roles and experiences with registries. Furthermore, once study data was collected, Cronbach's alpha was used to evaluate the internal consistency reliability of the indexes. The translation and validation is described in detail in **Supplementary File 1**.

Respondents and procedure

All Danish hospital departments providing cardiac rehabilitation and who report data to the Danish Cardiac Rehabilitation Database (N=30) were included in the study. Potential respondents included frontline staff from the multidisciplinary cardiac rehabilitation teams, mid-level managers and heads of departments.

The roles of the individual staff members can vary according to local arrangements, but in general, frontline staff collect and feed data into the registry, while managers on both levels are politically expected to take on a leading role in use of data for quality improvement [25]. Thus, while respondents were strategically chosen based on position, we also aimed to identify the frontline staff members who were most informed about the registry.

The respondents were identified through official websites, or when not available, by contacting each department directly, retrieving name, sex, work e-mail address and position. Invited frontline staff from each department included: a cardiac rehabilitation nurse coordinator, a physiotherapist, and a dietitian. A nurse manager and a chief physician were invited to represent the mid-level management, and finally, the heads of the departments included the leading physician, leading nurse and leading physio/occupational therapist. Some departments did not have all the frontline staff-members and managerial positions; consequently, between 4 and 8 individuals from each department were invited.

The survey questionnaire was distributed electronically by e-mail in May 2018 (software: SurveyXact, Rambøll Management, Århus, Denmark (www.surveyxact.dk). In case of nonrespondence two reminders were sent, after 7 and 14 days, respectively. A separate, singlequestion survey was e-mailed to remaining non-responders asking about the reasons for not responding to the survey.

Statistical analyses

Descriptive statistics were used to characterize respondents and non-respondents (sex, profession, role in relation to the registry and number of years in this role).

Item and index scores were calculated as raw scores and as dichotomized scores, where 'Agree' and 'Strongly agree' were merged and coded 'Agree' and the remaining two or three response categories were coded 'Do not agree'. The index scores were stratified and presented according to the different groups of staff (Frontline staff, Mid-level management, Head of department), and after checking data for normal distribution with histograms and quantile-quantile plots, the non-parametric tests Kruskall-Wallis and Wilcoxon signed-rank test was used to investigate if differences existed between groups.

Multiple linear regression analysis was used to investigate the factors facilitating use of data for quality improvement work for the different groups of staff respectively and combined. The index 'the healthcare unit's use of registry data' was used as the dependent variable and the five other index scores in the QWAQ as independent variables. Furthermore, a single variable "I am motivated to improve the cardiac rehabilitation care we provide as a result of our results in the registry" was included to further assess individual motivation [9,26].

147

All analyses were performed using STATA statistical software version 15.0 (StataCorp. 2017. Stata Statistical Software: Release 15. College Station, TX: StataCorp LLC). A significance level of 0.05 was applied.

Ethics

Prior to conducting this study permission to translate and cross-cultural adapt the QWAQ was obtained from the copyright holders (Ann Catrine Eldh and Ulrika Winblad). The study was approved by the Danish Data Protection Agency through Region Zealand, REG-149-2015. No ethical approval was necessary according to Danish law, and return of a completed questionnaire was regarded as giving consent to participation in the study.

RESULTS

Participants

Out of the 30 departments, 28 were represented in this study. A study flow diagram is presented in **Figure 1**. The survey was sent to 175 individuals of whom 101 responded (58%), of which 62 were frontline staff, 19 mid-level managers and 20 heads of departments (**Table 1**). Response proportions differed among the different groups of staff, with 78% of frontline staff responding and 35% of heads of departments. Characteristics of respondents and nonrespondents are presented in **Table 1**.

Figure 1. Study flow diagram



Table 1. Characteristics of	respondents ar	nd non-respondents
	Respondents	Non-respondents
	n=101	n=74
	n (column %)	n
Sex		
Female	88 (87%)	51
Male	13 (13%)	23
Group of staff		
Frontline staff (nurses,	62 (61%)	18
physiotherapists,		
dietitians)		
Mid-level management	19 (19%)	19
(nurse managers and chief		
physicians)		
Head of department	20 (20%)	37
(leading physician, leading		
nurse, leading physio-		
occupational therapist)		
Role within the registry *§		
Locally responsible	23 (23%)	#
Enters data	44 (44%)	#
Collects data	21 (21%)	#
Manager	24 (24%)	#
Other	17 (17%)	#
No. of years in this role *		
< 1 year	11 (11 %)	#
1-2 years	20 (21%)	#
> 3 years	66 (68%)	#
*Self-reported.		
§ Multiple responses possible.		
#Data not available for non-respon	ndents	

Most respondents were female (87%), aged 41 years or older (84%), with three or more years of experience with their role in the registry (68%). Among non-respondents, 33 (mainly managers) reported not having sufficient knowledge concerning the registry to respond to the survey questionnaire. No other reasons for non-response were reported, although two managers stated that they, besides insufficient knowledge, did not have enough time.

The extent of data use in local quality improvement work

The distribution of responses to each item, dichotomized with a cut-off at 'Agree', is shown in **Table 2**. There were significant variations in the responses of frontline staff, mid-level managers and heads of departments concerning resources for analysing data and performing improvement work, perceived support from own department, the degree to which they take part in analysis of data and report to others, and perceptions of departments use of data to identify areas for change.

Table 2. Distribution Rehabilitation Regis	1 of responses to items in the QWAQ* questionn try	aire by st	aff group:	s in hospi	ital depar	tments wo	orking wi	th the Da	nish Cardi	ac
		Number	r of respo	ndents wj	ho 'Agree	? and 'Stro	ongly agre	ee' ** (nu	mber (%))	
		Frontli	ne staff	Mid-lev manage	el ment	Heads o	f dept.	All resp	ondents	
Items		n=62	Missing	n=19	Missing	n=20	Missing	n=101	Missing [*]	p-value§
I believe the care of our cardiac rehabilitation patients	is of high quality	51 (81)	3 (5)	16 (84)	2 (11)	19 (95)	1(5)	85 (84)	6 (6)	0.19
	has sufficient resources to maintain a high quality	29 (47)	3(5)	11 (58)	2 (11)	12 (60)	1(5)	52(52)	6 (6)	0.30
I consider our results in the Danish Cardiac Rehabilitation Registry to be	('Good' or 'Very good', measured on 5-point likert scale ranging from Very poor – Very good)	25 (40)	3 (5)	7 (37)	2 (11)	14 (70)	1 (5)	46 (46)	6 (6)	0.10
Data from the registry	are of high quality	14 (23)	4(6)	3 (16)	2 (11)	8 (40)	1 (5)	25 (25)	7 (7)	0.46
	capture the essential aspects of quality of care	22(35)	3(5)	8 (42)	2 (11)	11 (55)	2 (10)	41(41)	7(7)	0.13
	are a useful tool for identifying improvement areas	30 (48)	3(5)	9 (47)	2 (11)	10 (50)	2 (10)	49 (49)	7(7)	0.73
	enable reliable internal comparisons over time	27 (44)	3(5)	8 (42)	3 (16)	9 (45)	2 (10)	44 (44)	8 (8)	0.53
	enable reliable external comparisons with other organisations registering in the Danish Cardiac Rehabilitation Registry	23 (37)	3 (5)	4 (21)	2 (11)	9 (45)	1(5)	36 (36)	6 (6)	0.65
We have sufficient resources (e.g. allocated time and competence) to	enter complete mandatory data in the registry	16 (26)	5 (8)	9 (47)	2 (11)	8 (40)	1 (5)	33 (33)	8 (8)	0.21
	analyse data from the registry	0(0)	5 (8)	4 (21)	2 (11)	5 (25)	1(5)	6(6)	8 (8)	0.03
	perform improvement work based on registry data	2(3)	6 (10)	5 (26)	2(11)	7 (35)	1(5)	14 (14)	(6) 6	0.03
My manager (the manager I report to)	calls for data from the registry	8 (13)	5 (8)	3 (16)	2 (11)	5 (25)	2 (10)	16 (16)	(6) 6	0.48
	supports improvement work initiated by others based on registry data	13 (21)	5 (8)	5 (26)	2 (11)	5(25)	2 (10)	23 (23)	(6) 6	0.77
	initiates improvement work bases on registry data	8 (13)	5(8)	4(21)	2 (11)	4 (20)	2 (10)	16 (16)	6 (6)	0.57
I get the support I ask for from	my own department	19 (31)	6 (10)	7 (37)	2 (11)	12 (60)	4 (20)	38 (38)	12 (12)	0.01
	support functions at the hospital	14 (23)	8 (13)	7 (37)	2 (11)	8 (40)	4 (20)	29 (29)	14 (14)	0.18
	the healthcare region	4(6)	8 (13)	1(5)	4 (21)	4 (20)	5 (25)	6(6)	17 (17)	0.10
	the Danish Clinical Registries (RKKP)	6 (10)	9 (15)	3 (16)	4(21)	2(10)	5 (25)	11 (11	18 (18)	0.44
	The Danish Cardiac Rehabilitation Database	22 (35)	7 (11)	5(26)	5 (26)	3(15)	5(25)	30 (30)	17 (17)	0.68
It is simple to	retrieve registry data	3(5)	7 (11)	3 (16)	2 (11)	2(10)	2 (10)	8 (8)	11 (11)	0.68
	explain our department s results to colleagues and managers	11 (18)	8 (13)	6 (32)	2 (11)	7 (35)	2 (10)	24 (24)	12 (12)	0.57

# Missing: median 9 (range	* QWAQ = the 'Quality impr ** Response options were on	I believe that what we gai resources spent on worki				by	Database are called for	Rehabilitation	Danish Cardiac	Our results in the												In my department, we									I	I am motivated to improv result of our results in the
6-18) § P-value calculated using Kruskall-Wallis test	ovement While Adopting Quality register outcomes survey' a five-point Likert scale (strongly disagree, disagree, neither	n from partaking in the registry justifies the ng with it	the healthcare region	the hospital board of directors	department managers	the department's members off staff					use registry data when introducing new clinical methods and procedures	use registry data to compare our results to similar organisations	members of staff	regularly present our results in the registry to	registry	deemed necessary bases on our results in the	meet to charge	use registry data to identify issues where there is a	perform own analyses of our data in the registry	use the registry indicators in the department's planning	all eligible patients	enter complete mandatory data in the registry for	manage improvement work in our organization by means of our results in the registry	registry	organization by means of our results in the	participate in improvement work in our	the registry	suggest improvements of our cardiac	report registry results to others	partake in analysis of registry data	retrieve registry data	e the cardiac rehabilitation care we provide as a e registry
	r agree nor o	9 (15)	4(6)	9 (15)	11 (18)	6 (10)					5 (8)	(CI) 6	5 (L-)	10 (16)		(67) oT	10(0)	16 (26)	9 (15)	15 (24)		43 (69)	4(6)	h 1		4(6)		5 (8)	1(2)	0 (0)	0(0)	16 (26)
	lisagree, ag	5 (8)	6 (10)	6 (10)	6 (10)	6 (10)					5 (8)	(s) (- (0)	5(8)		(o) C	7 (0)	6 (10)	6 (10)	(s) (- (2)	5 (8)	5(8)	h 		5(8)		6 (10)	6 (10)	5(8)	5(8)	7 (11)
	ree, strongly	7 (37)	6(32)	8 (42)	7 (37)	2 (11)					3 (16)	o (32)	(4 (21)		(33) ot	10 (10)	9 (47)	5 (26)	9(47)		17 (89)	5 (26)	- -		5 (26)		4 (21)	5 (26)	4 (21)	0 (0)	6 (32)
	agree), whe	1 (5)	2 (11)	2 (11)	2 (11)	2 (11)					2 (11)	2 (II)		2 (11)		(11) 7	2 (11)	3 (16)	2 (11)	2 (II)		2 (11)	2 (11)	,	,	2 (11)		2 (11)	3(16)	3 (16)	3(16)	2 (11)
	re not other	6 (30)	5(25)	7 (35)	10 (50)	6 (30)					6 (30)	7 (35)	1 (2-)	6 (30)		(0C) OT	10 (-0)	12 (60)	8 (40)	(0C) OT		17 (85)	3 (15)		(, , ,	3 (15)		1 (5)	1(5)	2 (10)	0 (0)	10 (50)
	wise indicat	2 (10)	1(5)	1(5)	(1(5))	2 (10)					1 (5)	(C) T	. (-)	1 (5)		(C) T	. (-)	2 (10)	1(5)	(C) I		1 (5)	1 (5)		į	1(5)		1 (5)	1(5)	1(5)	1(5)	1 (5)
	ed.	22 (22)	15 (15)	24 (24)	28(28)	14 (14)					14 (14)	22 (22)		20 (20)		კი (კი)	00 (00)	37 (37)	22 (22)	34 (34)		77 (76)	12 (12)	, ,	,	12 (12)		10 (10)	7(7)	6(6)	0(0)	32 (32)
		8(8)	9(9)	(9)	9(9)	10 (10)					8(8)	8 (8)	0.02	8(8)		0(0)	0 (0)	11 (11)	(9)	8 (8)	2	8 (8)	8(8)			8(8)		9(9)	10 (10)	9(9)	9(9)	10 (10)
		0.21	0.09	0.09	0.11				(0.23	0.26	0.20)	0.67		0.14		0.02	0.29	0.08	5	0.12	0.14			0.14		0.25	0.01	0.01	0.47	0.58

The mean score on the dichotomized indexes responses are presented in **Table 3**. For "Unit's use of data" (min 0, max 7), frontline staff scored a mean of 1.3 (SD=2.0), mid-level management a mean of 2.4 (SD=2.3), and heads of departments a mean of 3.0 (SD=2.5). Testing for analysis of variance between the three groups of staff (i.e. frontline staff, mid-level management and heads of departments) revealed that there were significant differences between the groups for three indexes: "Unit's use of data" (p=0.006), "Resources" (p=0.04) and "Management request for registry data" (p=0.006) (**Table 3**). The disagreements were in all circumstances found between frontline staff and the two groups of managers. As there were no disagreements between mid-level management and heads of departments, we decided to merge these two respondent groups to a new group: Management, for use in the multiple linear regression analysis.

Indexes	Max score	Mean sco	ores (Standard D	eviation)	Kruskall -Wallis	t-test (W	/ilcoxon´s r	anksum)
		Frontline staff	Mid-level management	Heads of dept.	p-værdi	Frontline/ Middle	Middle/ Head	Head/ Frontline
Use of data:					•			
Unit´s use of data	7	1.3 (2.0)	2.4 (2.3)	3.0 (2.5)	0.006	0.036	0.466	0.004
Aspects of registry u	se – inde.	xes:						
Data quality and usefulness	5	1.9 (1.8)	1.7 (1.9)	2.4 (2.0)	0.495	0.604	0.263	0.355
Support *	5	2.1 (1.0)	2.0 (1.5)	2.2 (1.5)	0.734	0.445	0.783	0.639
Resources	4	0.8 (0.7)	1.5 (1.5)	1.6 (1.5)	0.037	0.065	0.874	0.028
Management request for registry data	4	0.5 (1.1)	1.3 (1.5)	1.4 (1.6)	0.006	0.012	0.858	0.006
Management involvement in registry-based quality improvement	2	0.4 (0.7)	0.5 (0.8)	0.5 (0.8)	0.858	0.625	0.927	0.709

The sum of non-dichotomized index scores are depicted in Supplementary file 2.

Facilitators for use of data

The multiple linear regression analysis for all respondents showed a statistically significant

association between the dependent variable "Unit's use of data", the indexes "data quality and

usefulness" (coeff. 0.22 p=0.019), "management request for data" (coeff. 0.40, p=0.008) and the single variable "I am motivated" (coeff. 1.63, p<0.001) (**Table 4**). The six independent variables together explained 56% of the total variance in "Unit's use of data" (R^2 =0.56).

Table 4. Assoc register outco	ciations b mes surv	etween Un vey'	nit´s Use of da	ta and in	dexes in 'Q	Quality improv	ement W	/hile Adopt	ting Quality
		All respon	dents		Frontline	staff		Mana	gers
Independent variables	Coeff.	p-value	95% CI	Coeff.	p-value	95% CI	Coeff.	p-value	95% CI
Data quality and usefulness	0.22	0.019	0.04 - 0.41	0.15	0.192	-0.08 - 0.38	0.43	0.027	0.05 - 0.81
Resources	0.28	0.080	-0.03 - 0.58	0.05	0.860	-0.55 - 0.65	0.23	0.276	-0.19 - 0.64
Management request for data	0.40	0.008	0.11 - 0.69	0.28	0.199	-0.15 - 0.67	0.30	0.210	-0.18 - 0.77
Management involvement in quality improvement work	0.46	0.083	-0.61 - 1.19	0.90	0.017	0.17 - 1.63	0.13	0.768	-0.75 - 1.00
Support (agree)	0.46	0.211	-0.27 - 1.19	0.31	0.490	-0.58- 1.20	0.87	0.214	-0.53 - 2.27
I am motivated (agree)	1.63	<0.001	0.89 – 2.36	1.66	<0.001	0.69 – 2.63	1.10	0.109	-0.26 - 2.47
Model fit (r ²)	0.56			0.49			0.61		
Coeff. = Coeffici model.	ent; 95%C	CI = 95% Con	fidence Interval	; r ² = The	percentage	of variation in th	e respons	e that is expl	ained by the

Analysing the frontline staff and manager group respectively, different aspects were important for use of registry data in the two groups. Among managers "Unit's use of data" was significantly associated with "data quality and usefulness" (coeff. 0.43, p=0.027), and among frontline staff, reported data use was associated with "management involvement in quality improvement work" (coeff. 0.90, p=0.017) and "I am motivated" (coeff. 1.66, p<0.001) (**Table 4**).

DISCUSSION

This study sought to survey the use of data from the Danish Cardiac Rehabilitation Database to determine the extent to which data are used for local quality improvement and what facilitates the use of these data. Findings indicate that data from the registry were used in local quality improvement work to a relatively limited extent. It was not possible to distinguish between high and low extent of data use per se, as there is no shared understanding of standards for use of data yet. It may be that such standards are unrealistic to establish and that data should always be judged on an

individual basis. In the current study, we regard the reported use of data to be relatively low because of the gaps between evidence and practice identified previously in nearly all departments providing cardiac rehabilitation in Denmark [18].

While the literature regarding use of quality registry data is sparse, our findings are comparable to the findings of Fredriksson et al. [6]. They studied the use of data in local quality improvement, according to physicians and managers in three Swedish CQRs (stroke, gallstone surgery and lung cancer), using the original version of the QWAQ. They found similar levels of reported use of data in the gallstone surgery and lung cancer registries, while it was higher in the stroke registry. The latter is considered to be more developed in terms of e.g. feedback with national benchmarks and validation of data [6]. Such a degree of maturity has been suggested as a possible explanation for differences in use of data between registries [5,6,27].

In the present study, a specific focus was on whether frontline staff and managers' perceptions of data use differed. Frontline staff reported use of data on a department level to be lower than that of their managers. We found no studies investigating the perceived extent of use of CQR data among frontline staff as a separate group, nor was it possible to establish which (if any) of the two groups were "right", i.e. whether responses correspond to objective measures of data use. In a previous study of a patient safety programme, managers were found to hold a more positive view of the effectiveness of the initiative than frontline staff [13]. Similar to the proposed explanation in that study, the different perceptions between users of the Danish Cardiac Rehabilitation Registry could be explained by managers' greater overview, having insight into quality improvement initiatives across the organization [13]. However, it could also be that managers simply do not know as much about registry use in practice as their frontline employees, resulting in overly optimistic estimates. Yet another possibility is that the managers' responses may be more influenced by social desirability bias, i.e. over-reporting of desirable behaviours. Data-driven quality improvement is high on the healthcare policy agenda and managers (particularly heads of departments) are likely aware that their organization is being benchmarked against others in annual reports and in other national,

publicly available data such as the National Healthcare Quality Programme [1]. Frontline staff, on the other hand, may not be faced with such pressure to apply data. Instead, they often focus on entering data [7].

While reported data use was positively associated with the quality and usefulness of data, management requesting data, and personal motivation, none of these aspects were rated highly by the respondents. These aspects have previously been documented as influencing effectiveness of feedback from registries [9] and thus would seem crucial to address and improve in order to maximize the chances of usage of registry data. The negative perceptions of data quality underscores the challenges of creating a CQR that captures the essential aspects of care in relevant quality indicators [3,9]. This may be particularly difficult in a field such as cardiac rehabilitation, where a large proportion of the clinical intervention centres on lifestyle changes and improving quality of life, and where socioeconomic vulnerability among patients may add specific barriers to the perceived validity of data [28].

In agreement with previous Swedish findings [12], resources, such as time and competencies, and receiving support were not associated with use of registry data. This may seem surprising, as it has been highlighted as potentially important by implementation frameworks such as the Consolidated Framework for Implementation Research [26] and contradicts previous reports [5,10,29]. Resources and support were also associated with use of data in univariate analyses (data not shown). Hence, it appears that resources and support are reduced in priority when compared to other aspects, reflecting a complex interplay of factors that influence the extent of data use. This complexity increases further when considering that different aspects seemed to be important for data use among frontline staff and managers. For the frontline staff, results give the impression that data are used more if a motivated member of the multidisciplinary team takes on a championing role, supported by the nearest manager. This contrasts with managers, for whom data quality emerged as a crucial facilitator. Either way, if time is indeed lacking, as suggested by the responses to single items in our survey, the logical consequence is that increased time for quality improvement would result in

reduced time for other activities such as seeing patients, possibly resulting in increased strain on the staff. Similarly, the suggested lack of competencies and support may have the consequence that quality improvement work is performed by staff with suboptimal skills.

While the QWAQ covers a range of facilitators for use of data [12], all potentially relevant facilitators cannot be investigated. This is a common limitation of survey research, where questionnaire developers must weigh precision against the response burden. Still, our survey has yielded important insights into the *relative* importance of different facilitators [30]. Further explanations concerning the use of CQR data can be derived from our previous qualitative studies in the cardiac rehabilitation field. For example, we have found that feedback data may not reach the frontline staff because it fails to pass through complex delivery pathways, staff may not know that local feedback data exists, and a culture supporting quality improvement may not have been established (Egholm et al.; Helmark et al.; articles in review). Other plausible explanations, suggested by our previous work and supported by other scholars, are that roles and responsibilities for acting on data are unclear and that there is a general lack of time and understanding regarding the use of CQRs in improvement work in healthcare [15,27]. Furthermore, clinicians tend to have their own perceptions of what constitutes quality of cardiac rehabilitation and may dismiss the defined indicators [31].

We regard it as important knowledge that nearly half of the survey non-responders stated that they could not respond due to lack of knowledge of the registry. The majority of these reports came from managers, particularly heads of departments. Although it cannot be expected that managers have detailed knowledge of CQR use in daily practice, policy documents emphasize that they should have a strong focus on data-driven quality improvement and intervene when quality targets are not met [25]. Knowledge of the registry including how to apply data in improvement work is important to be able to link efforts to mission and strategic objectives, to allocate responsibilities and secure resources, and to motivate employees [32]. It has been highlighted previously, that managers often have inadequate knowledge and spend too little time on quality improvement to meet these important objectives [32,33]. Among those who did respond to our survey, frontline staff and

managers had different perceptions of some aspects of using the registry, suggesting a risk of misalignment between the two groups about optimal use of the registry [13,15], hence limiting registry effectiveness. However, it is important to recognize that frontline staff and managers did agree on several aspects, e.g. low data quality and data usefulness. Thus, staff and managers' perceptions may be more similar than staff expect (Egholm et al., article in review) and could be a platform for dialogue about how to progress and improve practice. The differing perceptions that we documented underscore the importance of accounting for perceptions of both groups when conducting quality improvement studies [13–15] to obtain a nuanced view from stakeholders in different positions and with different prerequisites for working with data-driven improvement.

Strengths and limitations

This is the first study to investigate how and to what extent data from a cardiac rehabilitation CQR is used for quality improvement, and is an important first step in understanding how these types of registries may contribute to improved quality of care. However, the fact that only one CQR for cardiac rehabilitation was included limits the generalizability of the findings. In addition, we do not know the extent to which the self-reported use of data correlates with actual use. Previous studies propose that actual use may be lower than study findings due to social desirability bias and response bias, as the most active registry users are most likely to respond [5,6].

The Danish Cardiac Rehabilitation Database was relatively new at the time of the study, having been in full operation for only three years. This time period is generally regarded as sufficient for implementation of a CQR according to the Danish Clinical Registries [23]. It may nonetheless have influenced the quality of the data in the registry, and furthermore, users may not yet have achieved full confidence in applying feedback data. However, full rounds of audit and feedback had been completed, and monthly updated feedback on indicators had been available for two years.

The sample size in the study was relatively small, but it still represents 93% of the cardiac rehabilitation units in Denmark and had an acceptable response rate of 58%. The survey had a broad participation of frontline staff, mid-level nurse managers and physicians, and department managers.

However, the reported low level of knowledge of the registry narrowed the number of relevant respondents to the survey. The sample size limited the statistical power of the analyses, thus restraining our possibility to include variables in the regression analyses.

CONCLUSION

This survey study among frontline staff and managers employed in clinical departments participating in the Danish Cardiac Rehabilitation Database indicate a relatively limited use of data from the database, where frontline staff reported use to be lower than that of their managers. Factors associated with use of data were the perceived data quality and usefulness, management request for data and personal motivation to use data. A difference between managers and frontline staff was found, as data quality and usefulness was important for managers reports of data use, while frontline staff reported use to be associated with their own motivation and with management involvement in quality improvement work. These findings suggest that a complex interplay of factors is associated with use of CQR data, with different aspects being important to different types of users. Furthermore, it emphasizes the need to include both managers and frontline staff when evaluating use of CQRs.

Although translation of the results from this study to other registries and settings should be done with caution, our results combined with the body of literature in the implementation science field suggest that whilst in the planning process of a new registry, the quality of the CQR and the readiness to receive it in practice should be carefully evaluated. Future studies should evaluate initiatives to enhance cardiac rehabilitation registries' data quality and relevance, and to build quality improvement capacity among clinical teams and their managers with regards to applying CQRs.

Funding: This work was supported by the Unit for Production, Research and Innovation, Region Zealand; the Department of Medicine, Holbaek University Hospital; The Danish Knowledge Centre for Rehabilitation and Palliative Care, University of Southern Denmark and Odense University Hospital, Southern Region of Denmark; and the Region Zealand Regional Research Fund. The funding bodies had no role in the design of the study, in the collection, analysis, and interpretation of data or in writing the manuscript.

Competing interests: CLE was functioning as a secretary for the chair of the Danish Cardiac Rehabilitation Database steering committee during work with the study. The study was independent, conducted apart from this role. CH is a board member of the steering committee for the Danish Cardiac Rehabilitation Database. ADZ is the Chair of the steering committee for the Danish Cardiac Rehabilitation Database. JC, UW, ACE, GB, and PN: No competing interests.

Author contributions: CLE, GB, ADZ, CH and PN designed the study. CLE, CH, UW and ACE took part in translation and cultural adaption of the survey. CLE conducted the survey, and together with JC performed the analysis, with the other authors being critical peers. CLE drafted the manuscript with intellectual contribution of all co-authors. All authors read and approved the final manuscript.

Data sharing statement: Data is available from the corresponding author upon reasonable request.

Acknowledgements: We are grateful to all the informants for taking their time to participate in the study. Thank you to Sarah Egelund Frausing and Tina Broby Mikkelsen for assistance with data collection.

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Supplementary file 1:

Cross-cultural translation and adaption of the 'Quality improvement While Adopting Quality register outcomes survey' and validation of the questionnaire indexes

CROSS-CULTURAL TRANSLATION AND ADAPTION

The 'Quality improvement While Adopting Quality register outcomes survey' [1] was translated from the original Swedish version to Danish using a widely recognized six-step methodology for cross-cultural translation and adaption of self-report measures [2]:

Step 1. Forward-translation into Danish: Two native-speaking Danish translators independently translated the questionnaire from Swedish to Danish. The first translator was a cardiac rehabilitation specialist nurse with experience of using and managing a clinical quality registry. The second translator (who was also the project manager) was experienced with questionnaire studies and methods, as well as quality improvement work, but had no clinical experience. Besides translating, the two translators made additional comments, highlighted challenging phrases, and marked uncertainties, each producing a written report.

Step 2. Synthesis of the Danish translations: The two translators met to discuss and solve discrepancies, and to create a consensus version. All discussions and decisions were documented in a report, written by the second translator.

Step 3: Back-translation into Swedish: Independently, and blinded to the original Swedish version, two translators back-translated the consensus version of the questionnaire from Danish to Swedish. Both translators were fluent Swedish speakers with extensive knowledge of the Swedish and Danish healthcare systems, but with no particular experience with clinical quality registries. One of them had a clinical background. Like the forward-translators, they translated the questionnaire as well as making additional comments, highlighting challenging phrases, and marking uncertainties.

Step 4: Expert committee review: An expert committee, including all the translators and the two developers of the original Swedish version of the questionnaire, reached consensus on a prefinal version based on all translators' reports. The group strived to achieve equivalence between the source and target version with regards to semantic, idiomatic, experiential, and conceptual equivalence, and both in items, response options and instructions.

Two examples:

There are no 'Regionalt registercentrum' (Regional Competence centres) in Denmark, but there are in Sweden (included in item 20-24 and item 27). This response-alternative therefore was translated into the nearest equivalent national centre in Denmark: 'Regionernes Kliniske KvalitetsudviklingsProgram (RKKP)' (The Danish Clinical Registries).

In Sweden, the word 'register' (registry) is a frequently used and accepted word for clinical quality registries. In Denmark, the word 'database' (database) is more commonly used whereas 'registry' is rarely used in daily clinical practice. Therefore, the committee reached consensus on using 'database' in the Danish version consistently throughout the questionnaire (multiple occurrences).

Step 5: Test of the pre-final version: The pre-final Danish version was field tested for acceptability, clarity and cultural applicability through cognitive interviews [2] among users of five different Danish clinical quality registries. These informants had different professional backgrounds (different clinical backgrounds and different positions in their departments, representing both frontline staff, middle level managers and head of departments) as well as different roles and years of experience with their respective registry (n=15), thus reflecting the target group of the present study. The informants were asked to fill out the questionnaire, and both think-aloud and verbal probing techniques were applied [3]. Comments were recorded in a report.

Finally, a few remaining issues were solved in the expert-committee.

Two examples:

Informants were unsure of what kind of support 'the healthcare region' could offer, and the majority did not know what 'The Danish Clinical Registries' was. As these response options nonetheless represent real support opportunity channels, and are near equivalents to the original Swedish options, they were kept in the questionnaire.

Many of the informants expressed a need for an 'I do not know' and/or 'Not applicable' response option for several of the items. For instance, if the informants had never retrieved data from the database, but was asked to state if they agreed on this being easy (item 29), they could not check a response option they found satisfactory. Instead, they skipped the item, or, alternatively, checked the "neither agree nor disagree" (neutral) response option on the 5-point Likert scale. The developers agreed that this sometimes would be an issue among Swedish registry users as well, but to keep the Danish version equivalent to the original Swedish version, no "I do not know' or 'Not applicable' response option was added.

Step 6. Submission of reports to the developers: Although the original developers had been part of the translation process, the written reports and translations were sent to them for their records. The developers approved the translated version.

INTERNAL CONSISTENCY OF INDEXES

Cronbach's alpha was used to evaluate the internal consistency reliability of the six indexes in the 'Quality improvement While Adopting Quality register outcomes survey' using survey data from the responders. Cronbach's alpha coefficients of 0.7 or higher were interpreted as acceptable [4].

Five of the six indexes showed acceptable internal consistency with Chronbach's Alpha coefficients between 0.74 and 0.92. The index 'Support from outer setting' had a slightly lower Chronbach's alpha (0.67) than the other indexes, and some difficulties responding to these items was indicated. We therefore decided to discard the use of the original version of the 'Support' index, and instead created a new, dichotomized 'Support' index: First, we created an index of all support sources (own department, support functions at hospital, healthcare region, the Danish Clinical Registries, or the DHRD database). As the kind of support received from these sources was not clear, and as we based on our knowledge of the field knew that one source could, in theory, supply all the necessary help, the second step was to dichotomize the 'Support' index. If the respondent had marked 'agree' or 'strongly agree' to receive the support he/she asked for from at least one of the five sources, it was rated as 'agree', if not, they did 'not agree' to receive support.

Index	Chronbach´s Alpha value
Unit´s use of registry data	0.9208
Data quality and usefulness	0.7995
Support from outer setting	0.6723
Resources	0.7464
Management request for registry data	0.9000
Management involvement in registry-based quality improvement	0.8785

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Supplementary file 2:

Raw index scores for Frontline staff, Mid-level management and Head of department

(The item responses were measured on 1-5 point Likert scales, where the response alternative 'Strongly disagree' equals a score of 1, 'disagree' equals a score of 2, and so forth)

Raw index scores for front department Indexes	line staf Max	f, mid-level man Mean scores (S	agement and head	d of
muches	score	Medil Scores (S		-)
		Frontline staff	Mid-level management	Head of dept.
Use of data:				
Unit's use of data	35	17.5 (6.6)	22.2 (4.4)	22.2 (5.9)
Aspects of registry use – index	es:			
Data quality and usefulness	25	16.0 (2.9)	16.3 (2.5)	17.1 (2.6)
Support *	25	15.5 (2.6)	16.4 (2.0)	16.2 (2.5)
Resources	20	10.3(2.5)	12.2 (3.2)	12.6 (2.6)
Management request for registry data	20	9.3 (3.7)	12.0 (3.6)	11.6 (4.2)
Management involvement in registry-based quality improvement	10	5.0 (2.0)	6.1 (1.3)	5.2 (2.2)
			.1 1	

*The Support index is the index we created consisting of 5 variables, not the original Swedish version with 3 variables

Appendices

Appendix I

DHRD indicators

Indicators in the Danish Card	diac Rehabilitation Database (2015-2017)	
Outcome measures	Proportion of patients	Standard
Participation in CR	participating in CR among all patients with diagnosed IHD, admitted to a dept. of cardiology	>35%
	with IHD continuing rehabilitation among CR participants	>75%
Exercise capacity	with IHD completing at least 80% of planned training sessions	>70%
	with IHD offered training sessions at the hospital, gaining at least 10% in exercise capacity	>80%
Smoking	with IHD nonsmoking at completion of CR among patients smoking at admission prior to rehabilitation	>60%
Dietary treatment	with IHD receiving dietary treatment by a clinical dietitian/MSc Clinical Nutrition	Undecided
LDL-cholesterol	with IHD which at the end of CR program has LDL-cholesterol <1.8 mmol/L or a 50% decrease	>60%
Blood pressure	with IHD which at the end of CR program has a consultation blood pressure below 140/90 mmHg	>70%
Screening for DM	with IHD and without diagnosed diabetes at admission, screened for diabetes at the end of CR	>90%
Screening for depression	with acute coronary syndrome who has been screened for depression by completion of CR	>80%
Antithrombotic therapy	with IHD receiving antiplatelet treatment by completion of CR	>95%
Statin therapy	with IHD receiving statin therapy by completion of CR	>80%
Beta-blocker therapy	with acute coronary syndrome receiving beta-blocker treatment by completion of CR	>80%
Abbreviations: CR=cardiac r lipoprotein	rehabilitation, DM=diabetes mellitus; IHD=ischemic heart disease; Ll	DL=low-density

Reference: Zwisler et al. The Danish Cardiac Rehabilitation Database. Clin Epidemiol 2016;25:451-6.

Appendix II

NACR indicators

National Certification Programme for CR (NCP_CR)

The NCP_CR is a joint initiative with the BACPR and NACR. It uses Key Performance Indicators (KPIs) based on NCP_CR agreed standards that relate to, but do not match, the BACPR Standards and Core Components (2017) to certify the quality of CR service delivery. Before any programme can be considered to be assessed against NCP_CR Key Performance Indicators they must be entering data into the National Audit for Cardiac Rehabilitation (NACR). Certification is achieved through meeting all 7 KPIs – the 3 Minimum Standards (1-3) and the 4 Standards based on national averages.

Minimum standard 1: Multidisciplinary team	At least three health professions in the CR team who formally and regularly support the CR programme
Minimum standard 2: Patient group	Cardiovascular rehabilitation is offered to all these priority groups: MI, MI+PCI, PCI, CABG, Heart Failure
Minimum standard 3: Duration	Duration of Core CR programme: \geq national median of 56 days.
Standard 4: National average for assessment 1	Percent of patients with recorded assessment 1: \geq England 80%; Northern Ireland 88%; Wales 68%
Standard 5: National average for CABG wait time	Time from post-discharge referral to start of Core CR programme for CABG: national median of \leq England 46 days, Northern Ireland 52 days, Wales 42 days
Standard 6: National average for MI/PCI wait time	Time from post-discharge referral to start of Core CR programme for MI/PCI: national median of \leq England 33 days, Northern Ireland 40 days, Wales 26 days
Standard 7: National average for assessment 2	Percent of patients with recorded assessment 2 (end of CR): \geq England 57%, Northern Ireland 61%, Wales 43%

The NACR annual report further includes the following patient outcomes:

CR contribution to: smoking cessation; physical activity status; Body Mass Index; Hospital Anxiety and Depression Scale anxiety levels; Hospital Anxiety and Depression Scale depression levels; normal health related quality of life.

Reference: The British Heart Foundation. The NACR annual report 2017.

Appendix III

Spørgeskema om hjerterehabilitering med fokus på den sygeplejefaglige indsats

Dette elektroniske spørgeskema handler om hjerterehabilitering med fokus på den sygeplejefaglige indsats på dit hospital. Dine besvarelser vil bidrage til kortlægning af de strukturelle forhold omkring hjerterehabilitering i Danmark ved opstart af den obligatoriske nationale kliniske kvalitetsdatabase: Dansk Hjerterehabiliteringsdatabase (DHRD).

Det tager omkring 15-20 minutter at udfylde spørgeskemaet. Du kan gemme og forlade skemaet undervejs. Skemaet er først afleveret når de sidste spørgsmål er udfyldt og der er trykket afslut.

Har du spørgsmål eller behov for hjælp til at udfylde skemaet er du velkommen til at ringe eller skrive til Forskningsassistent Henriette Knold Rossau tlf. 2965 5582, e-mail hekr@si-folkesundhed.dk.

Afgivelse af svar

besvarelser

Indledningsvis har vi brug for nogle enkelte informationer om dig, som udfylder det elektroniske spørgeskema.

1. Er du den person, som det elektroniske spørgeskema oprindeligt var stilet til?						
(Angiv kun ét svar)						
Ja - Gå til 4						
🗅 Nej						
2. Angiv dit navn						
3. E-mailadresse						
4. Angiv et telefonnummer som vi kan træffe dig på, såfremt der er behov for uddybning af dine						

5. Hvilken funktion har du i forhold til hjerterehabilitering på dit hospital?

(Angiv kun ét svar)

- Leder af afdelingen
- Leder for hjerterehabiliteringsgruppen/-teamet

Sygeplejerske med ansvar for hjerterehabilitering i dagligdagen

Andet

Indhold af hjerterehabilitering på dit hospital

De første spørgsmål handler om det overordnede indhold af hjerterehabilitering på dit hospital, som det ser ud lige nu.

I de følgende afsnit vil du blive bedt om at svare på spørgsmål om patientundervisning, psykosocial støtte og rygeafvænning. I særskilte spørgeskemaer indsamles oplysninger om de øvrige elementer af rehabiliteringen hos jer.

Spørgeskemaet afsluttes med spørgsmål om dokumentation og kvalitetssikring af den sygeplejefaglige hjerterehabiliteringsindsats hos jer.

Hvis jeres tilbud ikke passer helt ind i de foruddefinerede kategorier vil vi bede dig om at beskrive tilbuddet så godt som muligt i de åbne svarmuligheder.

6. Hvilke komponenter indgår i hjerterehabiliteringstilbuddet hos jer?

(Angiv gerne flere svar)

- Opstart af rehabiliteringsindsats under indlæggelse
- Systematisk henvisning af visitering af patienter rehabilitering
- Individuel vurdering og tilrettelæggelse af rehabiliteringsforløb
- Fysisk træning
- Patientundervisning
- Psykosocial støtte

	Støtte til rygeophør
	Diætvejledning og støtte til kostomlægning
	Systematisk indsats i forhold til risikofaktorkontrol (ex. blodtryk, dyslipidæmi, diabetes)
	Individuel afslutning og viderevisitering
	Systematiseret indsats med henblik på arbejdsfastholdelse
Ande	t

7. Arbejder afdelingen med socialt differentieret hjerterehabilitering?

(Angiv kun ét svar)

Nej

Ja, hvis ja bedes du uddybe hvordan differentieringen foregår:

Patientundervisning

Her følger en række spørgsmål om patientundervisningen hos jer.

Hvis jeres tilbud ikke passer helt ind i de foruddefinerede kategorier vil vi bede dig om at beskrive tilbuddet så godt som muligt i de åbne svarmuligheder.

8. Har afdelingen mulighed for at tilbyde/henvise hjertepatienter til patientundervisningsforløb?

(Angiv kun ét svar)

🗋 Ja

Nej - Gå til 17

9. Hvordan er patientundervisningen tilrettelagt hos jer? (Angiv gerne flere svar) Individuel undervisning Undervisning på hold Praktisk træning, ex. indkøb, madlavning mm. E-learning Telemedicin Andet _____ _____ 10. Angiv antal undervisningsgange patienten sædvanligvis møder til hos jer

 Antal

 Antal undervisningsgange:

 Varighed af lektioner i minutter:

 Antal uger undervisningen strækker sig over:

 Uddybende kommentarer

 Uddybende kommentarer

 11. Hvilke emner indgår i afdelingens patientundervisning?

 (Angiv geme flere svar)

Betydning af livsstil (Kost, rygestop, alkohol, motion)

	Motivation og livsstilsændring
	Undervisning i hjertesygdomme
	Håndtering af hjertesygdom
	Undervisning i seksualitet og hjertesygdomme
	Psykiske reaktioner
	Medicinbehandling
	Råd og vejledning om sociale forhold
Andet	t

12. Er afdelingens patientundervisning baseret på særlig teori (fx. Parse's teori) eller metode (fx. Stages of Change el. sundhedspædagogik)?

(Angiv kun ét svar)

🗋 Nej

Ja (angiv hvilken/hvilke):

 Hvilke personalegrupper indgår i afdelingens patien 	ntundervisning?
---	-----------------

(Angiv gerne flere svar)

- Læger
- Sygeplejersker
- Diætister
- Fysioterapeuter

	Psykologer
	Pædagoger
Ande	ŧ
14. Hvilk	e hjertepatientgrupper får tilbudt patientundervisning hos jer?

(Angiv gerne flere svar)		
	Post-AMI	
	Post Non-STEMI/post ustabil angina pectoris	
	Post-CABG/PCI	
	Angina pectoris	
	Hjerteinsufficiens	
	Hjerteklapopererede	
	Hjertetransplanterede	
	Patienter som har fået implanteret ICD	
	Højrisikopatienter	
Andr	e patientgrupper	

15. Vil patienter med følgende problemstillinger blive indkaldt til tilbud om patientundervisning?
(Angiv kun et svar pr. spørgsmål)

Ja

Nej
Ikke-dansktalende personer	
Personer med kognitive udfordringer	
Personer som har et betydeligt alkoholoverforbrug eller andet misbrug	
Personer ældre end en given alder	

Hvis personer ældre end en given alder ikke indkaldes, angiv venligst aldersgrænse:

16. Må pårørende til hjertepatienter også deltage i afdelingens tilbud om patientundervisning?

(Angiv kun ét svar)

- Ja, i alle sessioner
- Ja, i udvalgte dele af tilbuddet
- Nej

17. Her kan du komme med uddybende kommentarer til patientundervisningen i din afdeling

Psykosocial støtte

Her følger en række spørgsmål om den psykosociale støtte til hjertepatienter som tilbydes hos jer.

Hvis jeres tilbud ikke passer helt ind i de foruddefinerede kategorier vil vi bede dig om at beskrive tilbuddet så godt som muligt i de åbne svarmuligheder.

18. Har afd	lelingen mulighed for at tilbyde hjertepatienter psykosocial støtte?
(Angiv kun	n ét svar)
	Ja
	Nej - Gå til 29
19. Hvorda	an foregår tilbuddet om psykosocial støtte i afdelingen?
(Angiv ger	me flere svar)
	Individuelle samtaler
	Gruppeundervisning
Andet	
20. Er afde	elingens tilbud om psykosocial støtte baseret på en særlig teori eller metode?
(Angiv kun	n ét svar)
	Nej
Ja, ang	giv hvilken/hvilke:
21. Hvilke	personalegrupper indgår i afdelingens tilbud om psykosocial støtte?
(Angiv ger	ne flere svar)
	Psykologer
	Sygeplejersker
	Læger
Andre	

22. Bliver hjertepatienter screenet for angst og depression i hjerterehabiliteringsforløbet?

(Angiv kun ét svar)

- 🗋 Ja
- Nej Gå til 26

23. Hvilket redskab bruges til at screene patienterne?

(Angiv gerne flere svar)

- Prime MD
- Hospital Anxiety and Depression Scale (HADS)
- Beck Depression Inventory (BDI/BDI-II)

Andet

-	_	 	 	 	 	_	_	 	 _	 	 _	 	 _	 	 	 	 		 	 	 	
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_	_	 		 	 	_	_	 	 _	 	 _	 	 _	 	 	 	 		 _	 	 	

24. Hvem giver patienten svar på angst og depression screening?

(Angiv ge	erne flere svar) Psykologer
	Sygeplejersker
	Læger
Ande	t

25. Hvordan planlægges det videre forløb for patienter, som får konstateret angst og/eller depression i forbindelse med rehabiliteringsforløbet?									
(Angiv ku	un ét svar)								
	Der påbegyndes behandling i hjerterehabiliteringsforløbet								
	Henvises til egen læge								
	Henvises til psykolog								
	Henvises til liaisonpsykiatrisk afdeling								
Ande	t, angiv:								

26. Hvilke hjertepatientgrupper får tilbud om psykosocial støtte hos jer?

(Angiv gerne flere svar)

- Post-AMI
- Post Non-STEMI/post ustabil angina pectoris
- Post-CABG/PCI
- Angina pectoris
- Hjerteinsufficiens
- Hjerteklapopererede
- Hjertetransplanterede
- Patienter som har fået implanteret ICD
- Højrisikopatienter

Andre patientgrupper

-	-	-		 		-	-	-			-	-	-	 		 -	-	-	_	 	 -	 	_	 	-	 		 _	 -
_	_	_	_	 	 		_	_	 		_	-	_	 	 	 		_	_	 	 _	 	 _	 	_	 		 _	 -
_	_	_	_	 	 		_	_	 	 	_	_	_	 	 	 	_	_	_	 	 _	 	 _	 	_	 	 	 _	 _

27. Vil patienter med følgende problemstillinger blive indkaldt til tilbud om psykosocial støtte?

(Angiv kun et svar pr. spørgsmai)		
	Ja	Nej
Ikke-dansktalende personer		
Personer med kognitive udfordringer		
Personer som har et betydeligt alkoholoverforbrug eller andet misbrug		
Personer ældre end en given alder		

Hvis personer ældre end en given alder ikke indkaldes, angiv venligst aldersgrænse:

 	 	 	 	 	-	 		-	-	-	_	 	 	 	 	 -	 	 	 _	 	 	
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28. Tilbydes pårørende til hjertepatienter psykosocial støtte?										
(Angiv ku	in ét svar)									
	Ja, som individuelt tilbud									
	Ja, sammen med patienten									
	Ja, både individuelt og sammen med patienten									
	Nej									
29. Her kan du komme med uddybende kommentarer til den psykosociale støtte som tilbydes til hjertepatienter i din afdeling										

Støtte til rygeophør

Her følger en række spørgsmål om afdelingens tilbud om støtte til rygeophør.

30. Har afdelingen mulighed for at tilbyde/henvise hjertepatienter til støtte med henblik på rygeophør?									
(Angiv kun ét svar)									
🔲 Ja									
Nej - Gå til 39									
31. Hvor kan hjertepatienter modtage støtte til rygeophør?									
(Angiv gerne flere svar)									
Hjerteafdelingen har et standardiseret tilbud									
Hospitalet har et standardiseret tilbud									
Kommunen har et standardiseret tilbud, som patienterne henvises til									
Patienterne opfordres til at søge tilbud i lokalområdet (ex. egen læge, apo	tek)								
Andet									
32. Hvordan er tilbuddet om støtte til rygeophør tilrettelagt på jeres afdeling/ho	spital?								
(Angiv gerne flere svar)									
Rygestopkursus på hold									
Individuelle samtaler med henblik på rygeophør									
Andet									

-	-	-	-	-	-	-	-	-	-	-	-	-			-	-	-	-	-	-			-	 	-	 	 	-	-	 		-	 -	 				-	 	-
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33. Indgå	år et eller flere elementer i tilbuddet om støtte til rygeophør i hjerterehabiliteringen?									
(Angiv g	erne flere svar)									
	Systematisk fagerstrømscore og nikotinsubstitution ordination									
	Udlevering af nikotinsubstitution under behandling									
	Måling af CO2 i udåndingsluft									
	Måling af spyt-cotinin									
Ande	et									
34. Er af	4. Er afdelingens tilbud om støtte til rygeophør baseret på en særlig teori eller metode?									
(Angiv k	un ét svar)									

Nej

Ja, angiv hvilken/hvilke:

35. Hvilke personalegrupper indgår i afdelingens tilbud om støtte med henblik på rygeophør?

(Angiv gerne flere svar)

Læger

Sygeplejersker





Sygeplejersker uddannede som rygestopinstruktører

Andet

36. Hvilke hjertepatientgrupper får tilbud om støtte til rygeafvænning?													
(Angiv g	(Angiv gerne flere svar)												
	Post-AMI												
	Post Non-STEMI/post ustabil angina pectoris												
	Post-CABG/PCI												
	Angina pectoris												
	Hjerteinsufficiens												
	Hjerteklapopererede												
	Hjertetransplanterede												
	Patienter som har fået implanteret ICD												
	Højrisikopatienter												
Andr	e patientgrupper												

37. Vil patienter med følgende problemstillinger blive indkaldt til tilbud om støtte til rygeafvænning i hospitalsregi?

(Angiv kun et svar pr. spørgsmål)

Ja

Nej

Ikke-dansktalende personer	
Personer med kognitive udfordringer	
Personer som har et betydeligt alkoholoverforbrug eller andet misbrug	
Personer ældre end en given alder	

Hvis personer ældre end en given alder ikke indkaldes, angiv venligst aldersgrænse:

38. Tilbydes pårørende til hjertepatienter støtte til rygeafvænning?

(Angiv kun ét svar)

- Ja, som individuelt tilbud
- Ja, sammen med patienten
- Ja, både individuelt og sammen med patienten
- 🗋 Nej

39. Her kan du komme med uddybende kommentarer til afdelingens tilbud om rygeophør

Afslutning, viderevisitering, dokumentation og kvalitetssikring

Her følger nogle spørgsmål om afslutning af rehabiliteringsforløbet, viderevisitering, dokumentation og kvalitetssikring.

40. Afslu	ittes hjerterehabiliteringsforløbet med en individuel samtale med en sygeplejerske?											
(Angiv k	un ét svar)											
	Nej											
	Ja, altid											
	Ja, for udvalgte patienter											
Ande	et											
41. Foregår der en systematisk viderevisitering af patienterne ved afslutning af hjerterehabiliteringsforløbet?												
(Angiv g	erne flere svar)											
	Nej											
	Ja, der skrives en specifik hjerterehabiliteringsepikrise til egen læge											
	Ja, udvalgte patienter henvises til tilbud i kommunen											
Ande	et											
42. Kom	mentarer til afslutning af hjerterehabiliteringsforløb											

Dokumentation, kvalitetssikring og personalekompetencer

De næste spørgsmål handler om hvordan den sygeplejefaglige indsats dokumenteres og kvalitetssikres, samt hvilke kompetencer der er hos den sygeplejefaglige gruppe i hjerterehabiliteringen.

43. Hv	43. Hvordan dokumenteres hjerterehabiliteringsindsatsen hos jer?											
(Angiv	(Angiv gerne flere svar)											
	Der indføres notat om patientjournal/EPJ											
	Oplysninger indføres i specialark											
	Oplysninger indføres i elektronisk database											
An	iden dokumentation											
_												
_												
44. Hv	ilke parametre indgår i kvalitetssikring af indsatsen?											
(Angiv	gerne flere svar)											
	Der foretages ikke systematisk kvalitetssikring											
	Ændringer i risikofaktorer/livsstil											
	Ændringer i fysisk funktion vurderet ved funktionstest											
	Ændringer i selvvurderet helbred/livskvalitet											
	Patienttilfredshed											
An	ndet											

45. Bruges en eller flere af nedenstående redskaber til at vurdere selvvurderet helbred/livskvalitet?

(Angiv gerne flere svar)

	Generisk måleinstrument (SF36/SF12, EQ5D)									
	Sygdomsspecifik måleinstrument (fx. MLHF, SAQ, MacNew, HeartQol, KCCG, andre)									
	Enkelt spørgsmål om selvvurderet helbred									
Ande	t skema									
46. Hvor lang tid bruges i gennemsnit per patient på at dokumentere og kvalitetssikre hjerterehabiliteringsindsatsen hos jer? (Angiv antal minutter)										
(Angiv va	(Angiv værdi mellem 0 og 60)									

47. Hvilke kompetencer/uddannelser kræves for at sygeplejersker kan varetage hjerterehabiliteringsfunktionen hos jer?

(Angiv gerne flere svar)

Der kræves ingen specifikke kompetencer

- Mangeårig klinisk erfaring med kardiologiske hjertepatienter
- Kardiologisk efteruddannelse
- Diplom- eller masteruddannelse
- Specifikke hjerterehabiliteringskurser

Andre kompetencer (angiv venligst):

_____ ______

Uddybende kommentarer

Du er nu ved at være færdig med spørgeskemaet om det fysiske træningstilbud på dit hospital.

Som afslutning vil vi bede dig om at overveje om der er nogle oplysninger eller udfordringer ved netop jeres hjerterehabiliteringstilbud, som vi ikke har fået belyst tilstrækkeligt i de stillede spørgsmål.

48. Her kan du komme med uddybende kommentarer til hjerterehabiliteringsprogrammet i afdelingen

Afslutning af spørgeskema

Du er nu færdig med spørgeskemaet om hjerterehabilitering med fokus på den sygeplejefaglige indsats. Husk at trykke afslut inden du forlader siden.

Har du spørgsmål eller kommentarer til kortlægningen af de strukturelle forhold omkring hjerterehabilitering på danske hospitaler er du velkommen til at ringe eller skrive til Forskningsassistent Henriette Knold Rossau tlf. 2965 5582, e-mail: hekr@si-folkesundhed.dk.

Appendix IV

Barrierer og muligheder for lokalt forbedringsarbejde

Dansk hjerterehabiliteringsdatabase (DHRD)

Dette spørgeskema indgår i et ph.d.-projekt, som sætter fokus på hvilke hindringer og muligheder der, er for at bruge data fra Dansk Hjerterehabiliteringsdatabase i et lokalt forbedringsarbejde. Det er vigtig viden, for at på sigt eventuelt at kunne forbedre databasen og støtten til at bruge data lokalt. Studiet gennemføres af ph.d.-studerende Cecilie Lindström Egholm, Syddansk Universitet.

Spørgeskemaet er til dig, der arbejder i en afdeling som bruger Dansk Hjerterehabiliteringsdatabase (DHRD). Der er 50 spørgsmål og det tager 10-15 minutter at besvare. Spørgeskemaet er inddelt i sektionerne A til G, som omhandler forskellige temaer indenfor arbejdet med databasen og forbedringsarbejde. Hvis du ønsker, kan du supplere med yderligere information i fritekstfelter.

Hvis du ikke når at blive færdig med udfyldelsen på én gang, er det muligt at vende tilbage til skemaet senere.

Har du spørgsmål til udfyldelsen, kontakt venligst undertegnede. Du kan også få spørgeskemaet tilsendt i papirversion.

Med venlig hilsen

Cecilie Lindström Egholm Ph.d.-studerende Videncenter for Rehabilitering og Palliation (REHPA), Syddansk Universitet e-mail: cegholm@health.sdu.dk Telefon: 2497 5436

	A	. Bag	lgrund	
1.	Jeg er:			
			Kvinde	
			Mand	
2.	Alder:			
			30 år eller yngre	
			31-40 år	
			41-50 år	
			51-60 år	
			61 år eller ældre	
3.	Jeg er:			
	(Det er muligt at sætte flere krydser	り		
			Læge	
			Sekretær	
			Sygeplejerske	
			Fysioterapeut	
			Diætist	
			Sosu-assistent	
			Afdelingsleder	
			Andet:(a	angiv hvad)
4.	Min rolle i arbejdet med DHRD er: (Det er muligt at sætte flere krydser	ŋ		
			Lokalt ansvarlig for databasen	
			Registrere data i databasen	
			Indsamler data til registrering i data	basen
			Afdelingsleder	
			Andet:(a	angiv hvad)
5.	Jeg har haft min nuværende rolle i ;	arbejde	t med DHRD:	
			Mindre end et år	
			1-2 år	
			3-5 år	

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Mere end 6 år

B. Behandlingskvalitet og adgang til ressourcer

Besvar spørgsmålene ud fra den behandling som patienter, der får hjerterehabilitering, tilbydes på dit hospital. Sæt kryds ved det svar som passer bedst med din opfattelse.

Jeg mener, at vores behandling af hjerterehabiliteringspatienter ...

	Meget uenig	Uenig	Hverken enig eller uenig	Enig	Meget enig
6. er af høj kvalitet					
 har tilstrækkelige ressourcer til at kunne udføres med høj kvalitet 					

Jeg mener, at...

	Meget dårlige	Forholdsvis dårlige	Hverken dårlige eller gode	Forholdsvis gode	Meget gode
8. xores resultater i DHRD er					

Hvis du har yderligere kommentarer til ovenstående spørgsmål, skriv venligst her:

C. Data fra databasen

Herunder følger fem spørgsmål om, hvordan du opfatter DHRD data. Sæt kryds ved den svarmulighed som passer bedst med din opfattelse.

Data fra databasen...

	Meget uenig	Uenig	Hverken enig eller uenig	Enig	Meget enig
9. er af høj kvalitet					
 fanger de vigtigste aspekter af kvaliteten i behandlingen 					
 er et godt redskab til at identificere områder, der bør forbedres 					
 muliggør valide sammenligninger over tid af vor afdelings behandling 					
13. muliggør valide sammenligninger med andre afdelinger som indberetter til DHRD					

Hvis du har yderligere kommentarer til ovenstående spørgsmål, skriv venligst her:

D. Organisatoriske forudsætninger for arbejdet med databasen

Herunder følger 15 spørgsmål om forudsætninger for at arbejde med data fra DHRD, ud fra et organisatorisk perspektiv. Sæt kryds ved den svarmulighed som passer bedst med din opfattelse.

Vi har tilstrækkelige ressourcer (fx tid og kompetencer), til at...

	Meget uenig	Uenig	Hverken enig eller uenig	Enig	Meget enig
 registrere de obligatoriske data i databasen 					
 analysere data-udtræk fra databasen 					
 gennemføre forbedringsarbejde baseret på data fra databasen 					

Min nærmeste leder...

	Meget uenig	Uenig	Hverken enig eller uenig	Enig	Meget enig
17. efterspørger data fra databasen					
 støtter forbedringsarbejde som andre har initieret på baggrund af data fra databasen 					
 19. initierer, forbedringsarbejde på baggrund af data fra databasen 					

Angiv hvor du henvender dig, når du har brug for hjælp til... (Det er muligt at sætte flere krydser)

	Egen afdeling	Hospitales støtte: funktioner	Regionen	RKKP*	DHRD
20. registrering af data					
21. udtræk af data					
22. analyse af data					
 forbedringsarbeide på baggrund af data 					

*Regionernes Kliniske Kvaltetsudviklingsprogram

Jeg får den hjælp jeg beder om fra...

	Meget uenig	Uenig	Hverken enig eller uenig	Enig	Meget enig
24. egen afdeling					
25. hospitalets støttefunktioner					
26. regionen					
27. Regionernes Kliniske Kvalitetsudviklingsprogram (RKKP)					
28. DHRD					

Hvis du har yderligere kommentarer til ovenstående spørgsmål, skriv venligst her:

E. Din anvendelse af data fra databasen

Herunder følger ni spørgsmål om, hvordan du opfatter din brug af data fra DHRD. Sæt kryds ved den svarmulighed som passer bedst med din opfattelse.

Det er nemt at...

	Meget uenig	Uenig	Hverken enig eller uenig	Enig	Meget enig
29. Jave udtræk af data fra databasen					
30. forklare afdelingens resultater for kollegaer og ledelse					

Jeg...

	Meget uenig	Uenig	Hverken enig eller uenig	Enig	Meget enig
 bliver motiveret til forbedringsarbejde på baggrund af vores resultater i databasen 					

Jeg...

	Aldrig	Sjældent	Nogen gange	Ofte
32. Javer udtræk af data fra databasen				
33. deltager i analyse af data fra databasen				
34. formidler databaseresultater til andre				
 foreslår forbedringsindsatser i afdelingen, baseret på vores resultater i databasen 				
 <u>deltager</u> i forbedringsarbejde i afdelingen baseret på vores resultater i databasen 				
 Jeder forbedringsarbejde i afdelingen, baseret på vores resultater i databasen 				

Hvis du har yderligere kommentarer til ovenstående spørgsmål, skriv venligst her:

F. Afdelingens anvendelse af data fra databasen

Herunder følger 12 spørgsmål om, hvordan I bruger data fra DHRD. Sæt kryds ved den svarmulighed som passer bedst med din opfattelse.

På min arbejdsplads...

	Meget uenig	Uenig	Hverken enig eller uenig	Enig	Meget enig
 registrerer vi obligatoriske data i databasen, for alle de patienter vi skal 					
 bruger vi indikatorer fra databasen i afdelingens planlægning 					
40. laver vi egne analyser af vores data fra databasen					
 bruger vi data til at identificere områder, hvor der er behov for forandring 					
 gennemfører, vi forbedringer, som vi mener er nødvendige på baggrund af vores resultater fra databasen 					
 præsenterer vi regelmæssig vores resultater fra databasen for afdelingens medarbejdere 					
44. <u>bruger</u> vi data fra databasen til at sammenligne vores resultater med lignende afdelinger					
 bruger vi data fra databasen, ved indførelse af nye kliniske metoder og rutiner 					

Vores resultater fra DHRD efterspørges af...

	Meget uenig	Uenig	Hverken enig eller uenig	Enig	Meget enig
46. afdelingens medarbejdere					
47. afdelingens ledere					
48. hospitalets ledelse					
49. regionens ledelse					

Hvis du har yderligere kommentarer til ovenstående spørgsmål, skriv venligst her:

G. Afsluttende spørgsmål

Afslutningsvis beder vi dig vurdere jeres indsatser i forhold til udbyttet af databasen. Sæt kryds ved den svarmulighed som passer bedst med din opfattelse.

Jeg mener at...

	Meget uenig	Uenig	Hverken enig eller uenig	Enig	Meget enig
 det udbytte vi får af at bruge databasen, kan retfærdiggøre de ressourcer vi anvender i arbejdet med databasen 					

Hvis du har yderligere kommentarer til ovenstående spørgsmål, skriv venligst her:

Appendix V







Date 04.04.2017

Information letter to participants

Title of research project: Implementation of clinical quality databases for cardiac rehabilitation in Denmark and England

Dear

We would hereby like to invite you, as a coordinator of cardiac rehabilitation services at your hospital, and a member of your staff to participate in a research project. The project aims at exploring health professionals' perceptions of putting a cardiac rehabilitation database into use in clinical practice. We include two countries: Denmark and England, and in England, the focus is on the National Audit of Cardiac Rehabilitation (NACR).

We are interested in your perceptions of working with the NACR in practice, both positive and negative. Knowledge about e.g. what hinders or facilitates use of the database can be applied to develop better databases and better support structures in the future. Furthermore, studies of how feedback from a database is perceived are very important in order to make the feedback as useful as possible in clinical practice.

The project is carried out by two Danish students: Cecilie Lindström Egholm as part of her PhD studies at the University of Southern Denmark, and Lotte Helmark as part of her Master of Public Health studies at the University of Copenhagen. The project is conducted in cooperation with the University of York. The project has been approved by the Danish Data Protection Agency.

If you choose to take part in the project, you and your staff member will each be asked to:

- Take part in an individual interview of about 45 minutes duration, at your workplace
- Sign an informed consent before onset of the interview.
- Fill out a brief pre-interview information sheet about you and your department, sent to you and returned to us by e-mail.

For practical reasons, we ask you to select and invite the member of your staff. He/she would need to have some practical experience with the NACR, and the professional background could be e.g. doctor, nurse, physiotherapist or dietitian.

The interviews will be audio recorded. All information collected during the research project will be treated confidentially and will be coded so that you and your unit/hospital remain anonymous. The information will be presented in written reports and/or academic journal articles, in which neither your identities nor your hospital's name will be revealed.

Participation in this project is voluntary and you are free to withdraw at any time without consequences for you or your department.

We hope that you would like to take part in the project. If you do, please contact PhD-student Cecilie Lindström Egholm, e:mail; ance@regionsjaelland.dk. If you have any questions about the research project or require further information, also please contact Cecilie.

Thank you for your time.

Yours sincerely,

Cecilie Lindström Egholm MScPH, PhD-student, University of Southern Denmark Lotte Helmark RN, MPH-student, University of Copenhagen