



# PhD Thesis

Hanne Winther Frederiksen

## Cardiac Rehabilitation Among Migrants

- A Mixed-Methods Study

Department of Internal Medicine, Copenhagen University Hospital, Herlev

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# **Cardiac Rehabilitation Among Migrants – A Mixed-Methods Study**

## **PhD thesis**

Hanne Winther Frederiksen, MHSc, RN

## **University of Copenhagen**

Department of Internal Medicine, University Hospital, Herlev

## **Assessment committee**

Associate Professor Maria Kristiansen (Chair)

Section for Health Services Research, Department of Public Health, University of Copenhagen, Denmark

Professor Mogens Lytken Larsen

The Faculty of Medicine, Department of Clinical Medicine, Aalborg University Hospital, Denmark

Professor Karien Stronks

Academic Medical Centre, Department of Public Health, University of Amsterdam, the Netherlands

## **Academic advisors**

Associate Professor Marie Nørredam

Danish Research Centre for Migration, Ethnicity and Health (MESU), Section for Health Services Research, Department of Public Health, University of Copenhagen, Denmark

Senior Researcher Tove Lindhardt

Department of Internal Medicine, Copenhagen University Hospital, Herlev, Denmark

Professor Ann-Dorthe Zwisler

Danish Knowledge Centre for Rehabilitation and Palliative Care (REHPA), University of Southern Denmark, Denmark.

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## Articles included in the thesis

- I. Frederiksen HW, Zwisler A-D, Johnsen SP, Öztürk B, Lindhardt T, Norredam M. Differences in initiation and discontinuation of preventive medications and use of non-pharmacological interventions after acute coronary syndrome among migrants and Danish-born. *Eur Heart J*. 30. april 2018
- II. Frederiksen HW, Zwisler AD, Johnsen SP, Öztürk B, Lindhardt T, Norredam M. Education of migrant and non-migrant patients is associated with initiation and discontinuation of preventive medications for acute coronary syndrome. *Submitted*.
- III. Al-Sharifi F, Frederiksen HW, Rossau HK, Norredam M, Zwisler AD. Access to cardiac rehabilitation and the role of language barriers in the provision of cardiac rehabilitation to migrants. *Submitted*.
- IV. Frederiksen HW Norredam M, Zwisler AD, Lindhardt T. Rehabilitation and everyday life among migrants with ischemic heart disease. *Submitted*.



# Summaries

## Summary

**Title:** Cardiac rehabilitation among migrants

**Aim:** The overall objective of the thesis is to gain insight into access to cardiac rehabilitation (CR) for migrants with ischemic heart disease (IHD) and into experiences with being a migrant patient in the intersection between different parts of the healthcare system. More specifically, substudies I-IV seek to answer the following research questions: Do migrant patients, diagnosed with acute coronary syndrome (ACS), differ from Danish patients in their use of CR and what role do sociodemographic factors and comorbidity play in use? (*Substudy I*). Is participation in patient education associated with higher medication persistence among ACS patients in general as well as among the subgroup of patients with a migrant background? (*Substudy II*). Do migrants have access to CR services; and are interpreter services and multilingual materials provided at hospitals and in municipalities? (*Substudy III*). How do Turkish and Pakistani migrants experience everyday life with IHD, how does CR support the achievement of good health, and what are the experienced barriers and enablers for use of CR. (*Substudy IV*).

**Methods:** *Substudy I* was a nationwide register study comparing use of preventive medications and physical exercise, dietary advice and patient education among Danish-born, Western and non-Western migrants, including the subgroups of Turks, nationals from the former Republic of Yugoslavia and Pakistanis. The study population was identified in the National Patient Register, and included subjects discharged with ACS from 2010 to 2014 (N=33,199). *Substudy II* assessed whether use of patient education was positively associated with use of preventive medications, and whether these associations were modified by migrant background. The study population was similar to that of substudy I; and in both substudies results were adjusted for comorbidity and sociodemographic factors. *Substudy III* was a descriptive survey study assessing provision of CR and the role of language barriers in access to CR in municipalities and hospitals. The surveys were conducted in 2013 and 2015 as parts of the data collection for the Danish National Cardiac Rehabilitation Database. *Substudy IV* was an explorative qualitative study including 16 interviewees from seven households of Turkish or Pakistani migrants with recent IHD. Interviews focused on everyday life, disease management, and experienced barriers and enablers for use of CR. The empirical material was analysed by thematic network analysis and by the theoretical framework of the Common-Sense Model of Self-Regulation.

**Results:** *Substudy I* found that, compared to Danish-born, non-Western migrants were less likely to initiate ADP- and ACE-inhibitors (RR: 0.93, 95% CI: 0.90;0.96 and 0.91, 95% CI: 0.87;0.96), and at greater risk of discontinuing all included preventive medications (OR: 1.52, 95% CI: 1.40;1.64 to 1.72, 95% CI: 1.46;2.02). Migrants were also less likely to have at least one contact for patient education (RR: 0.95, 95 % CI: 0.92;0.98), and had significantly fewer contacts for physical exercise and patient education, albeit differences in median number of contacts were small or absent (median 7 vs. 9,  $p < 0.001$ , and median 4 vs. 4,  $p = 0.011$ ). Similar patterns were found among the Turkish, nationals from the former Republic of Yugoslavia, and Pakistani subgroups, although differences were attenuated among Turkish-born. *Substudy II* found that use of patient education was associated with higher initiation of preventive medications (RR: 1.15, 95% CI: 1.14; 1.17 to 1.30, 95 % CI: 1.27; 1.33) and lower risk of discontinuation of statins (HR: 0.86, 95% CI: 0.79;0.92), beta-blockers (HR: 0.92, 95% CI: 0.88;0.97) and ACE-inhibitors (HR: 0.89, 95% CI: 0.80;0.98). Stratification according to migrant background, showed effect modification on initiation, but not on discontinuation. *Substudy III* found language barriers in access to CR; and non-Danish speaking patients had only access to interpreter services in 84 % ( $n=26/31$ ) of the included municipalities, in contrast to 100% (19/19) of the hospitals. Multilingual information material was provided in 3% ( $n=1/31$ ) of the municipalities, and 32% ( $n=6/19$ ) of the hospitals. *Substudy IV* found that Turkish and Pakistani migrants with recent IHD experienced illness to conflict with their usual role in society and in the family. Furthermore, if healthcare services and lifestyle changes did not take the social and cultural context of the individual into consideration, they were experienced as less useful and difficult to implement in everyday life. Lifestyle and other routines were connected to social and cultural belongingness, and routines that reinforced social belongingness might be prioritized over lifestyle changes aimed at avoiding potential future health threats. Lastly, relatives' role in access to healthcare was described as essential.

**Conclusion:** Inequalities in use of CR and preventive medications were identified; and socio-demography and comorbidity could not explain the lower use among migrants. Barriers to access were identified at both patient and provider levels, and related to poor family finances, language, knowledge and gender. Barriers were also ascribed to low acceptability of healthcare services; and migrants described difficulties with the implementation of lifestyle changes if changes conflicted with the norms and routines of migrants' social and cultural contexts. Lastly, it was found that education is likely to be effective in improving medication persistence among migrant as well as non-migrant patients with recent IHD.

## Resumé (Danish summary)

**Titel:** Hjerterehabilitering blandt indvandrere

**Formål:** Det overordnede formål var at få indsigt i adgang til hjerterehabilitering (HR) for indvandrere med nyligt opstået iskæmisk hjertesygdom (IHS), og indsigt i oplevelser med det at være patient med indvandrerbaggrund i brudfladerne mellem forskellige dele af sundhedsvæsenet. Mere specifikt søgte jeg med substudierne I-IV at besvare de følgende forskningsspørgsmål: Er der forskelle mellem patienter med indvandrerbaggrund og danskfødte i brug af HR, og hvilken rolle spiller komorbiditet og sociodemografiske faktorer? (*Substudie I*). Er deltagelse i patientuddannelse forbundet med højere vedholdenhed i medicinbrug blandt patienter med akut koronart syndrom (AKS) samt specifikt blandt AKS-patienter med indvandrerbaggrund? (*Substudie II*). Har indvandrere adgang til HR, og tilbydes der tolk samt flersproget informationsmateriale på hospitaler og i kommuner? (*Substudie III*) Hvordan oplever tyrkiske og pakistanske indvandrere hverdagslivet med IHS, hvordan støtter HR opnåelse af sundhed, og hvad er de oplevede barrierer og facilitatorer for adgangen til HR? (*Substudie IV*).

**Metoder:** *Substudie I* var et nationalt registerstudie, der sammenlignede patienters vedholdenhed med brugen af forebyggende medicin samt fysisk træning, diætvejledning og patientuddannelse blandt danskere, vestlige og ikke-vestlige indvandrere, inklusiv subgrupperne tyrkere, ex-Jugoslaver samt pakistanere. Studiepopulationen identificeredes i det Nationale patientregister (NPR) og inkluderede individer udskrevet med AKS i årene 2010-2014 (N=33,199). *Substudie II* undersøgte om brug af patientuddannelse var positivt associeret med vedholdenhed med medicin, og om det at patienter havde indvandrerbaggrund modificerede mulige associationer. *Substudie II* inkluderede samme population som *substudie I*, og resultater begge fra substudier blev justeret for komorbiditet og sociodemografiske faktorer. *Substudie III* var et deskriptivt surveystudie, der undersøgte adgang til HR for ikke-dansktalende patienter, om der blev tilbudt tolk og flersproget informationsmateriale i kommuner og på hospitaler. Surveydata indsamledes som del af dataindsamlingen til Dansk Hjerterehabiliteringsdatabase i 2013 og 2015. *Substudie IV* var et eksplorativt kvalitativt interviewstudie, som inkluderede 16 interviewpersoner fra syv familier, hvor et familiemedlem havde nyligt opstået IHS. Guidede interviews blev udført i interviewpersoners hjem og fokuserede på hverdagsliv, sygdomshåndtering, og oplevede barrierer og facilitatorer for brug af HR. Det empiriske materiale blev analyseret ved hjælp af tematisk netværksanalyse, og med *the Common-Sense Model of Self-Regulation* som teoretisk referenceramme.

**Resultater:** *Substudie I* fandt, at ikke-vestlige indvandrere, sammenlignet med danskere, i mindre grad startede ADP- og ACE-hæmmere (RR: 0.93, 95 % CI: 0.90;0.96 og 0.91, 95 % CI: 0.87;0.96), og havde større risiko for at ophøre med alle inkluderede typer medicin (OR: 1.52, 95 % CI: 1.40;1.64 til 1.72, 95 % CI: 1.46;2.02). Ikke-vestlige indvandrere var også i større risiko for slet ikke at deltage i patientuddannelse og havde signifikant færre kontakter for fysisk træning og patientuddannelse, selvom forskellene i medianer var små eller ikke-eksisterende (median 7 vs. 9,  $p < 0.001$ , og median 4 vs. 4,  $p = 0.011$ ). Et lignende mønster blev fundet for de tyrkiske, ex-jugoslaviske og pakistanske subgrupper, men med større forskelle blandt tyrkere. *Substudie II* fandt at patientuddannelse var forbundet med højere sandsynlighed for at AKS-patienter påbegynder medicin (RR: 1.15, 95 % CI: 1.14; 1.17 til 1.30, 95 % CI: 1.27; 1.33), og mindre risiko for at de ophørte med stationer (HR: 0.86, 95 % CI: 0.79;0.92), beta-blokkere (HR: 0.92, 95 % CI: 0.88;0.97) og ACE-hæmmere (HR: 0.89, 95 % CI: 0.80;0.98). Stratificering i forhold til indvandrerbaggrund viste effekt modifikation for start af medicin, men ikke for risiko for at ophøre. *Substudie III* fandt, at der var sproglige barrierer i adgang til HR idet ikke-dansktalende patienter kun havde adgang til tolk i 84 % ( $n=26/31$ ) af de inkluderede kommuner mod 100 % (19/19) af hospitalerne. *Substudie IV* fandt, at tyrkiske og pakistanske indvandrere med nyligt opstået IHS oplevede, at sygdommen var i konflikt med deres hidtidige rolle i samfundet og i familien. Det oplevedes, at sundhedsydelser og livsstilsændringer, som ikke tog højde for kulturelle og sociale kontekster, var svære at implementere i dagliglivet. Livsstil og andre rutiner havde betydning for individets sociale og kulturelle forbundethed, og rutiner, som forstærkede social forbundethed kunne blive prioriteret frem for livsstilsændringer, der sigtede mod at forebygge potentielle fremtidige sundhedsproblemer. Ydermere oplevedes det, at pårørende havde en central rolle i at fremme patienternes adgang til sundhedsydelser.

**Konklusion:** Der blev fundet uligheder i adgangen til HR og forebyggende medicin mellem indvandrere og danskfødte, og komorbiditet og sociodemografi kunne ikke forklare den lavere brug blandt indvandrere. Barrierer i adgang til HR og forebyggende medicin var til stede både på patient- og yderniveauer, og var relateret til økonomi, geografisk afstand, sprog, køn og viden. Barrierer kunne også være relateret til hvor acceptable sundhedsydelser opleves, og hvis ydelser ikke tog højde for kulturel og social baggrund kunne de være svære at implementere i hverdagen. Dog er der indikationer på at deltagelse i patientuddannelse fremmer patienters vedholdenhed med forebyggende medicin blandt danskfødte, såvel som blandt indvandrere

## Thesis at a glance

	Substudy I	Substudy II	Substudy III	Substudy IV
<b>Level</b>	Population	Population	System	Individual
<b>Theme</b>	Comparison of use of CR and preventive medications	Evaluation of the effects of a patient education intervention	The role of language barriers in migrants' access to CR	Experiences with CR and everyday life
<b>Domains of the Tanahashi framework</b>	Contact coverage	Effectiveness	Accessibility	Availability, Accessibility and Acceptability
<b>Methods</b>	Register	Register	Survey	Qualitative
<b>Main findings</b>				
<b>Danish-born</b>	Reference	Patient education is associated with initiation and discontinuation of preventive medications	Short education, substance abuse, mental disorder, and limited social network are evaluated as predictive for vulnerability in the CR-trajectory.	Not included
<b>Non-Western</b>	Lower initiation and higher risks of discontinuation of medications, lower initiation of patient education, fewer contacts for physical exercise and	Initiation of medications is associated with use of patient education.	Interpreter less frequently available in municipalities compared to full coverage in hospitals. Multilingual information material is rarely used.	Only Turkish and Pakistani non-Western migrants were included. See below

	patient education			
<b>Turkish migrants</b>	Lower initiation and higher risks of discontinuation of medications, lower initiation of physical exercise, dietary advice and pt. education, fewer contacts for patient education	Included in the non-Western subpopulation but not studied separately	Studied as part of the group of non-Danish speaking patients	IHD conflicts with the individual's role in society and the family. There is a need to take the social and cultural contexts into consideration, and relatives enable access to CR.
<b>Pakistani migrants</b>	Lower initiation and higher risks of discontinuation of medications, fewer contacts for physical exercise and patient education	Included in the non-Western subpopulation but not studied separately	Studied as part of the group of non-Danish speaking patients	IHD conflicts with the individual's role in society and the family. There is a need to take the social and cultural contexts into consideration, and relatives enable access to CR.

Inspired by O'Cathain's Mixed-Methods matrix

# Introduction

In Nordic welfare states, patients with ischemic heart disease (IHD) are entitled to the benefits of highly specialized healthcare, and North European healthcare systems have undergone substantial improvements over the last decades. However, interconnected to the improvements an increasing specialization throughout the healthcare trajectory is taking place, which reinforces fragmentation of care, and is likely to conflict with the aims of holism and integration of care (1). The increasing fragmentation of care is critical, especially for patients who encounter particular barriers in access to healthcare, and who find it difficult to navigate the system, or who do not enjoy the benefits of having relatives with the power to speak their cause. Patients with a migrant background may be particularly vulnerable due to many different but entangled factors relating to socio-psychology, socio-economy and/or the migration history (2–4). By definition, migrant patients come from different and perhaps less developed healthcare and educational systems with different rules and codes of conduct. Some are not fluent in the local language and some do not have relatives to help them navigate through healthcare systems in times of illness. The healthcare trajectory for patients with recent IHD is an example of a highly specialized trajectory from the onset of disease and until long-term sustainment of life-style changes. The cornerstones in secondary prevention of IHD are cardiac rehabilitation (CR) and preventive medications, with the latter at times being described as an integrated part of the CR programme. The aims of CR are to support and encourage patients to manage their disease, to be adherent to preventive medications, and to return to an active and satisfactory life, as defined by the individual. CR is a complex intervention involving different health professions such as cardiologists, nurses, physiotherapists and dieticians, it takes place in both primary and secondary healthcare sectors, and includes interventions related to physical exercise, dietary advice and patient education. (5–8).

This thesis is about migrants to Denmark with recent IHD and their use of CR. Thus, the thesis is placed in the intersection between migrant health and cardiac rehabilitation research but is also about access to inter-sectorial healthcare services for vulnerable populations, and a contribution to the body of research on equality in health. Given the focus on equality in health, the thesis can also be seen as a contribution to international goals and commandments concerning health and equality (9,10), such as Universal Health Coverage (11,12) and the right to health, as stated in the International Covenant on Economic, Social, and Cultural Rights (13).

The thesis is a mixed-methods study, encompassing register-, survey- and qualitative interview data, with a cross-cutting focus on migrants with recent IHD. However, the substudies zoom in on different problem-areas or different subpopulations, e.g. with a particular focus on patients with acute coronary syndrome (ACS) in the register studies, and a particular focus on migrants born in Turkey or Pakistan in the qualitative interview study.

## **Aims and research questions**

The overall objective of the thesis is to gain insight into access to CR for migrants with IHD, and into experiences with being a migrant patient in the intersection between different parts of the healthcare system. More specifically, substudies I-IV seek to answer the following research questions:

1. Do migrant patients, diagnosed with ACS, differ from Danish patients in their use of CR, and what role do sociodemographic factors and comorbidity play in use?
2. Is participation in patient education associated with higher medication persistence among ACS patients in general as well as among the subgroup of patients with a migrant background?
3. Do migrants have access to CR services; and are interpreter services and multilingual materials provided at hospitals and in municipalities?
4. How do Turkish and Pakistani migrants experience everyday life with IHD, how does CR support the achievement of good health, and what are the experienced barriers and enablers for use of CR?

## **Background**

In the following, important concepts of the thesis will be presented, followed by a more thorough conceptual description of the heterogenic group of migrants and of health impacts of migration, of IHD, and of the content and organization of CR in a Danish setting.



## Migrants in Denmark

I have chosen to categorize the population in scope of my research as migrants, classified according to country of birth. I use the International Organization for Migration's (IOM) definition, stating that a migrant is: *"any person who is moving or has moved across an international border or within a state away from his/her habitual place of residence, regardless of (1) the person's legal status; (2) whether the movement is voluntary or involuntary; (3) what the causes for the movement are; or (4) what the length of the stay is"* (14). Also, in accordance with IOM, I use the term 'migrant' which covers both persons moving to (immigrants) and away from (emigrants) his/her habitual place of residence. On the numbers, IOM estimates that there are currently 240 million international migrants, and migrants form 10% of the populations in many EU-countries (14). In Denmark, migrants form 10% of the population, out of which 58% originate from non-Western countries. The most frequent non-Western emigration countries are Turkey, Pakistan, Ex-Yugoslavia, Iraq, Lebanon, Somalia, Eritrea, Afghanistan and Syria. The share of migrants in Denmark is expected to increase over the course of the next 40 years (15). I wish to emphasize that the use of the migrant category is a choice, and that there is no consensus on the appropriate terms for the studies of migrants, ethnic minorities or racial groups, which are the most common concepts for classifications within the research field. I chose to operate with the migrant category because it refers directly to the person's life-course and calls for explorations of the meaning of moving from one country to another. Moreover, the concept is widely used; and substudies I and II are based on the extensive Danish population registers containing information on country of birth, immigration and emigration. For historical reasons, and to avoid misuse as it happened during World War II, it is not allowed to store data on ethnicity in Danish registers. In this context, the term migrants is therefore the most accurate categorization because we have rather precise information on people's country of birth, while ethnic groups might differ within countries of birth, e.g. the ethnicity of Turkish-born might be Turkish, Kurdish, Arab, Armenian, Greek, Ladino and many more, albeit the majority of Turkish-born migrants to Denmark are ethnic Turks or Kurds.

I therefore operationalize the migrant category by using Statistics Denmark's definition of migrants, implying that *a migrant is an individual who is born outside of Denmark and whose parents are both non-Danish* (15). Statistics Denmark categorizes further into Western and non-Western migrants, where the latter refers to all migrants who are not born in Western Europe, North America or Australia (16). I have also used the Western-/ non-Western categorizations

but seek to acknowledge the heterogeneity of these groups by dividing further into subpopulations at country of birth wherever applicable. Country of birth is defined according to the following rules: When both parents are known, country of birth is defined by the mothers' country of birth; when only one parent is known, country of birth is defined by country of birth of this parent; and when none of the parents are known, by the persons' own indication.

Although the division into country of birth might be the most precise categorization, these groups are smaller than the Western/non-Western categories; and their use introduces higher risks of type II errors, implying that we might be unable to show significant differences in the comparative register studies.

### **Danish immigration history**

Post-World War II immigration to Denmark has been dominated by waves of influxes of refugees and labour migrants: Following the Soviet invasion of Hungary in 1956, approximately 1000 Hungarians immigrated to Denmark. The next immigration wave started during the economic boom in the late 1960's and continued into the beginning of the 1980's when immigration laws were changed. The majority of migrants to Denmark during this period was labour migrants and family reunified to these, mainly from Turkey, Pakistan and the former Republic of Yugoslavia. Hereafter, migration flows have been affected by refugee-producing conflicts, such as the Balkan conflicts in the 1990's, and most recently, the conflicts of Iraq, Afghanistan, Syria and Eritrea. Migration to Denmark, other than by refugees, mainly consists of students and labour migrants from other EU-countries, and of family reunification migrants (17). Drivers for migration are traditionally divided into push and pull factors. War, poverty and persecution are classical push factors, whereas pull factors are those related to expectations of better opportunities in the recipient country, such as jobs, social and economic safety, education, and family bonds. In reality, migration processes are often driven by both push- and pull factors to a varying degree, and as described, migration to Denmark has been driven by both. Nevertheless, from a health perspective it is relevant to consider main drivers for migration because health is affected by factors such as war, persecution and uncertainty, but migrants mainly driven by pull-factors may also experience health effects of migration. In substudies I and IV I zoom in on the subpopulations of migrants born in Turkey, the former Republic of Yugoslavia and Pakistan, of which many migrated to Denmark on the grounds of prospects of labour.

### **Turks, nationals from the former Republic of Yugoslavia and Pakistanis, and their living conditions in Denmark**

The body of literature concerning the health of the larger groups of low-skilled labour migrants arriving to Denmark from the late 1960s to the beginning of the 1980s is sparse (17). Mirdal has explored psycho-somatic complaints of Turkish migrant women in Denmark (18,19), and Liversage and Jakobsen, the socio-economic and psycho-social circumstances of elderly Turkish migrants in a life-course perspective (20). Both studies described marginalized groups struggling with cultural clashes, poor economy and a longing for their countries of origin. Liversage and Jakobsen applied qualitative as well as register data and were hereby able to demonstrate the interconnectedness between life in exile, low education, Danish legislation, low-skilled work and disease in a life-course perspective, where the accumulation of a lifetime of disadvantages have contributed to very difficult living conditions, e.g. 29% of the elderly Turkish migrants living below OECD poverty levels, against only 1 % of the elderly Danish-born (20). To my knowledge, no similar studies exist concerning the Pakistani and former Yugoslavian groups of labour migrants in Denmark, but there is reason to believe that at least the socioeconomic circumstances are comparable across these groups of low-skilled labour migrants. The group of nationals from the former Republic of Yugoslavia immigrated to Denmark in two waves: Firstly, simultaneous with the Turkish and Pakistani subgroups in search for low skilled jobs, and secondly, as refugees following the Balkan War during the years 1991 to 2001 (17). Post-migration circumstances vary between the groups of labour migrants and refugees since integration programmes including Danish language courses were not systematically offered to migrants during the 1960' and 1970's, but introduced in the late 1980's prior to the arrival of the second wave of migrants from the former Republic of Yugoslavia. Hence, the living conditions of many of these labour migrants and other non-Western migrants in Denmark are formed by the accumulation of disadvantages, as described by Liversage and Jakobsen (20). Furthermore, migrants are at the centre of a shifting political discourse, which has taken place in Denmark during the last three decades. In his analysis of Danish immigration discourse, Yilmiz explored how group classifications of migrants emphasize cultural rather than economic attributes, and how heterogeneity among migrants is flattened into an illusion of alien sameness (21). It is further demonstrated how attention is directed toward conflicts over cultural norms, and away from conflicts over resources and rights, which excludes migrants from the classical fight for equality and workers' rights, which has been a cornerstone in the construction

of Scandinavian welfare states. The health consequences of such marginalization-processes are likely to be extensive, as shown in a large-scale UK study, finding reported experience of discrimination to have independent health effects (22).

## **Health impacts of migration**

The group of non-Western migrants is heterogeneous, but there are different migration-related factors that may cause a vulnerability associated to experiencing more unmet health needs or health-related outcomes that differ from those of local-born populations. For example, the challenge of manoeuvring in a healthcare system that one is not familiar with, originating from a country with less developed healthcare- and educational systems or experiencing language barriers.

In the following, considerations related to factors affecting the health status of migrant populations will be touched upon. Stronks et al suggest a conceptual framework for describing factors contributing to good or poor health among migrants, and operate with proximal risk factors and characteristics of the ethnic group (4). Firstly, divergent disease incidence or prognosis of health problems between migrants and local-born may relate to risk factors that are considered to be linked or proximate to the onset of disease and include physical (e.g. housing conditions), behavioural (e.g. physical activity), psychosocial (e.g. stress), biological (e.g. hypertension), and, much in the scope of this thesis, the access migrants enjoy to healthcare of good quality. Second, these proximal risk factors are not linked to migrant groups by coincidence, and causal pathways leading to the uneven distribution of risk factors must be considered. The distribution of proximate risk factors may relate to characteristics of the migrants that are attributional to the group such as genetic profile or cultural identity, and to the relationship between migrants and society, including socio-economic position, migration history, ethnic identity, and/or discrimination (4). Specifically, for the causal pathways to migrants' risk of developing IHD, socio-economy is an umbrella term for many lifestyle and living conditions which can be both risk factors for developing IHD and contribute to marginalization and unhealthy changes in behaviour (23). For factors related to the migration history, previous studies have found that length of stay predicts ill cardiovascular health (24–26), and acculturation plays an important role, since migrants who adapt the most to Western lifestyle, experience the largest increase in IHD risks (27).

## **Migrants' access to healthcare**

A major topic in migrant health research concerns the access migrants enjoy to effective, appropriate and well-coordinated healthcare (28). Several of the attributional and/or relational factors listed by Stronks et al. explain the causal pathways leading to divergent use of healthcare. E.g. migrants' access to healthcare can be determined by perceptions of when to seek healthcare that are pertinent to the culture, socio-economic factors such as education and financial factors, migration history, such as length of stay or a history of torture or other traumatic events. Perceived discrimination may also cause reluctance from the migrant to seek healthcare; and health professionals' and/or society's discriminatory practices may decrease accessibility to healthcare services. Findings on the use of healthcare among migrants tend to show that migrants are disadvantaged, but considerable variation has been found between different migrant groups, healthcare services and countries (29). In order to understand these patterns, it is central to acknowledge that access to effective healthcare requires more than simply providing the service, but is also determined by the presence of barriers and enablers and by effectiveness of the intervention (28).

Reviews on access to healthcare for migrants find that barriers on the patient level are often related to socio-economic, socio-cultural and migration-related factors like e.g. health beliefs, economic limitations, social support, health literacy and language (3,28). Barriers on the provider level have been related to stereotyping, uncertainty, and lack of knowledge; and on the system level to lack of time and resources for translation, loss of data in inter-sectorial transitions, and a tendency towards more specialism, which might challenge appropriate and individualized care (30). CR is an inter-sectorial disease management programme which requires coordination throughout the treatment trajectory. CR therefore possesses a build-in risk of being hard to access for some migrants, according to the barriers on the patient, provider and system levels (6–8,31). In the following, I draw a short outline of the incidence of IHD, CR and existing evidence of effectiveness, and potential barriers to use of CR, specific for migrants with IHD.

## **IHD among local-born and migrants in Europe**

This thesis focuses on IHD defined as chronic or acute ischemia of the heart, including the ICD-10 codes I20-I25 (angina pectoris, acute and subsequent myocardial infarction (ST elevation and non-ST elevation), other acute ischemic heart diseases and chronic ischemic heart disease (32). In the register studies, focus is delimited to acute coronary syndrome (ACS), which is a severe

acute event caused by myocardial infarction with or without ST-elevation (STEMI)/ (NSTEMI) or by unstable angina pectoris (33,34). Cardiovascular diseases (CVD) account for 37% of all deaths in the EU, with IHD as the leading cause accounting for approximately 13% of CVD-deaths (35,36). In 2015, approximately 13 million people were living with IHD in the EU, but age-standardized prevalence rates tend to be decreasing in Northern and Western European countries; and age-standardized survival rates after IHD have been increasing in Northern European countries since the beginning of the new millennium (35). In Denmark, the incidence of IHD in 2015 was 27 946 cases, and age-adjusted prevalence rates were 1 939 per 100 000 for men, and 986 per 100 000 for women. For comparison, the mean age-adjusted prevalence rates for high income countries in Europe were 2 267 per 100 000 for men, and 1 212 per 100 000 for women (36).

The observed increases in survival after IHD are associated to changes in life style and improved possibilities for diagnosis, treatment and secondary prevention (36). Thus, for general populations in Northern and Western Europe, trends in IHD seem to be moving in the right direction, albeit socio-economic inequalities remain an issue to be addressed in both majority and minority populations (37,38). Among migrants in Denmark and Northern Europe in general there is not a consistent picture of IHD occurrence. Incidence, prevalence and mortality largely depend on country of origin, data availability (e.g. death certificates vs. register-based data vs. sample based studies), and health status of the comparison population (39,40).

### **Cardiovascular risk factors among migrants in Europe**

Evidence on risk factors among migrants living in Denmark is limited to a survey study on health behaviour, reporting that non-Western migrants had higher intake of vegetables, lower alcohol intake, and were less physical active, compared to Danish-born (41), non-peer-reviewed reports with similar findings (16,42), and two studies finding higher diabetes prevalence, compared with Danish-born (43,44). Other Scandinavian studies on IHD risk factors in migrant populations include a Norwegian study, finding that migrants from Sri Lanka, Pakistan, Iran, Vietnam and Turkey had higher levels of triglycerides, total cholesterol, waist-to-hip ratio and BMI compared with Norwegian-born (45). In Sweden, migrants were found to have higher rates of obesity than Swedish-born (46,47); and Arabic-speaking migrant men were more likely to be smokers than Swedish-born men, whereas it was opposite for women (48). In other North European countries, a Dutch study found more hypertension, diabetes and obesity among migrants, as compared with the Dutch (49); and a German study found smoking patterns similar

to the Swedish, with more Turkish males and fewer women being daily smokers, as compared with German-born (50). In general, diabetes incidence, prevalence and mortality are higher among migrants compared with local born, in particular among migrants of South Asian descent (43,44,49,51,52). For all risk factors, the occurrence tends to converge towards the host population with time spent in the immigration country (25,27,47,50). Other evidence on the significance of societal context of the host country comes from comparative cross-national studies on the prevalence of hypertension, type II diabetes and metabolic syndrome in ethnic minority groups living in the Netherlands and the UK, which found that ethnic minorities in the Netherlands were more disadvantaged than ethnic minorities in the UK (51,53,54).

### **Morbidity from IHD among migrants**

Relative risks with local-born Scandinavians as reference are diverging; Danish studies have found higher incidences among migrants from Turkey, Pakistan, and the former Republic of Yugoslavia, but not among migrants from Somalia, Latin America or Sub-Saharan Africa (55,56). In Norway, higher IHD-prevalence was found among migrants from Sri Lanka, Pakistan, Iran, Vietnam and Turkey (45); and higher AMI-incidence was found among South-Asians, nationals from the former Republic of Yugoslavia and Central Asia, whereas lower incidences were found among migrants from North Africa, Sub-Saharan Africa, South-East Asia and East Asia (57). In Sweden, Turkish, Syrian and South Asian migrants were found to have higher AMI-incidence (58). Other studies on the prevalence of IHD among non-Western migrants residing in European countries are likewise heterogeneous (40,53,59,60), but Dutch studies have found that inequalities between local-born and migrants are highest among subjects below 70 years of age and that the downward trend in IHD incidence in general populations is not reflected in migrants of Turkish and Moroccan origin (61,62). These findings may reflect the aforementioned findings that length of stay in immigration countries and adaptation to a Western lifestyle predict ill cardiovascular health.

### **Mortality from IHD among migrants**

Some studies have found migrants to be advantaged in IHD-mortality (25,27,39,63,64), while other studies have found similar mortality risks among migrants and local-born (65); and some have found higher short-term and long-term mortality among migrants (59,66). Rafnsson et al. combined CVD mortality data from the Netherlands, Spain, France, Scotland, England & Wales, and Denmark, and found rates which differed according to region of origin, with higher mortality

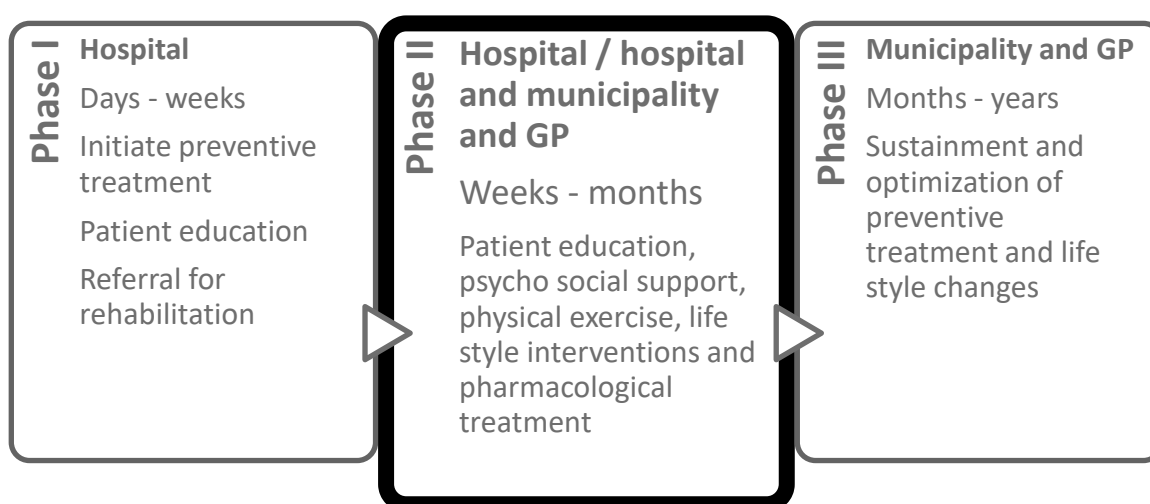
among migrants from North Africa, Sub-Saharan Africa, South Asia, and Turkey, and lower rates among migrants from Latin America and East Asia when compared to native populations (40). The study formed part of the Migrant and Ethnic Health Observatory (MEHO) project (60). By comparing migrant populations from the same countries of origin, living in different European countries, the MEHO-project found higher mortality rates among Turkish-born living in Denmark, than their Turkish peers living in France, the Netherlands and Sweden, suggesting that there exist substantial potentials for improvements in prevention of CVDs in Denmark (60). Furthermore, the studies indicate that differences in mortality from CVD, including IHD, can to some extent be explained by differences in living conditions and risk factors in the immigration countries. To sum up: In the evaluation of IHD risks among migrants, we need to take a multitude of factors into consideration; and it is beyond the scope of this thesis to fully unfold and disentangle them. Nevertheless, migrants' use of CR and preventive medications is key to reducing morbidity and mortality, and in the following I give a brief introduction to core components of these secondary prevention interventions.

## **Cardiac rehabilitation**

In UN's Convention on the Rights of Persons with Disabilities, all countries are encouraged to organize, strengthen, and extend comprehensive rehabilitation services and programmes (67), and in WHO's World Report on Disability, rehabilitation is defined as: "*A set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environment*" (5). The aims of CR are to improve the patients' level of functioning, remove or reduce activity-related symptoms, reduce level of disability, and enable the patient to return to a position in society which is satisfactory to the individual. Cardiac rehabilitation is a multi-factorial intervention recommended by international guidelines to patients with IHD (33,34,68). According to the Prevention of CVD Programme of the European Society of Cardiology (ESC), core components in cardiac rehabilitation include patient assessment, physical activity counselling, physical exercise, dietary counselling, risk factor control, patient education, psychosocial management, and vocational advice (69). There is evidence that CR is effective in reducing cardiovascular mortality and that it may also reduce risk of readmissions, and improve health related quality of life (6,7,70,71). In practice, the provision of CR is heterogeneous across and within countries (72–74), but in general, CR starts from the day the patient is hospitalized, is divided into phases I, II and III, encompassing the



following (**Figure 1**): Phase I (4-5 days) diagnosis and treatment at the hospital and referral for further CR; phase II (8-12 weeks) physical exercise, dietary counselling, risk factor control, patient education, psychosocial management, and vocational advice. In Denmark; Phase II is either the responsibility of the hospital, the municipality and GP, or shared between the three, according to local agreements and individual needs of the patients (75). Phase III encompasses life-long sustainment and optimization of life style changes and pharmacological treatment. Responsibility of phase III is in general shared between GPs and municipalities (8). Thus, the patients' trajectory through CR is depending on actions taken by healthcare providers in both primary and secondary sectors and by the individual patient. In order to study migrants' use of CR it is therefore necessary to consider relevant factors in different sectors throughout the CR trajectory, from referral to initiation and long-term sustainment and optimization. In this thesis, focus is on phase II of CR.



**Figure 1: Chronology and distribution of responsibility in Danish cardiac rehabilitation**

Several studies have found that use of CR, defined as the patients' active participation in scheduled activities, is low. In cohort studies from the Netherlands and Belgium, use of CR has been found to be 16 and 12 %, respectively (76,77). A survey on CR in Denmark found use to be around 50 %, but only 3 % of the patients participated in all CR services (78). Low use of CR has been associated with older age, female sex, distance to the provider, comorbidity (77), low socioeconomic status, being unmarried or living alone, health beliefs (78–81) and physicians'

lack of endorsement of CR (82). Several studies have investigated interventions to improve use of CR, and a few had promising results (83,84).

To date, the literature on migrants' use of CR in the European context is sparse. A large register study from the UK did not find ethnic minority background to be a predictor for low use of CR, but the study was prone to selection bias, because it only included subjects who had participated in at least one session (85). Another UK-based study on use of CR among under-represented groups found that data on ethnic minorities were too sparse to evaluate formally, and therefore suggested that this group was unlikely to be referred to or to join programmes (86). North American studies have included ethnic minority status and are heterogeneous with regards to associations to referral and use of CR (79,80,87). Conclusively, the studies call for more research on ethnic minority patients' use of CR. A recent Cochrane review on interventions to increase use of CR in general populations, concluded that there was some evidence to suggest that interventions targeting patient identified barriers may increase the likelihood of success, but that few practice recommendations could be made due to few studies on the subject (83). Some studies have focused on interventions to improve use of CR among social disadvantaged groups (88–90), but apart from the role of language barriers (88) and the need for patient-endorsed appropriate physical training for South-Asian women (90), there is a lack of studies that specifically address barriers and enablers for use of CR among migrant groups in the setting of a Nordic welfare state.

## **Preventive medications**

Secondary prevention in recent IHD includes pharmacological treatment with aspirin, statins, adenosine diphosphate receptor inhibitors (ADP-inhibitors) and  $\beta$ -blockers, as well as angiotensin converting enzyme inhibitors (ACE-inhibitors) in selected patients (33,34). Patients' adherence to preventive medications is among the strongest modifiable predictors for survival in IHD, but there is room for improvement in general IHD-populations (33,34,91,92). The evaluation of adherence to medications must include information on patients' initiation, implementation, and discontinuation of medication (93), and as such, many studies, including substudies I and II of this thesis, are delimited to study medication persistence, defined as time from initiation and until discontinuation.

Like many other predictors for good health, medication persistence is related to social status (91) and a few studies have assessed persistence among migrants with IHD (94–97). Although not

consistently, most studies found lower persistence among migrants compared to local-born, but studies have either been underpowered (96), included migrant populations that differed from those of the Nordic welfare states, included incomplete data, or applied weak statistical methods (94,95,97). Lastly, it is not clear whether the observed differences could be explained by sociodemographic confounders.

## **Analytical frameworks**

Access to CR and preventive medications among migrants with IHD in the context of a Nordic welfare state is an area in need of investigation; and in doing so, I must take patient, provider and system-related factors into consideration. It must be acknowledged, that patients' access to healthcare is more than mere availability of the services but must also include considerations on the process of accessing and subjective and objective perspectives on quality and effectiveness. I seek to acknowledge and conceptualize this complexity of factors affecting healthcare use by applying a mixed-methods design; and by discussing the concept of effective access through the lens of the Tanahashi framework for effective coverage of healthcare. Both of these analytical frameworks are introduced in the following.

### **Mixed-methods design**

The study of access to care should not be limited to the investigation of use or 'receipt of care', but should also consider the process of accessing care, the acceptability of care, and the quality of care (9,28). I sought to consider this by identifying overall differences in use, effect of and barriers to CR, along with an exploration of the individuals' encounters with the healthcare system. Furthermore, I wanted to produce knowledge that could have some implications for practice and could guide us towards more inclusive services of higher quality, and hereby meet the needs of groups that encounter barriers in their use and benefits of healthcare.

I sought to meet these aims by applying a mixed-methods design. The register studies could inform us on use, effect and contributing factors, the survey on barriers at the provider-level, and the qualitative approach on experiences of everyday life, including unmet needs, experienced usefulness of healthcare services and potential areas for improvements of CR.

Mixed-methods design is generally most valuable when there is an integration of results from the different substudies, whereby the research contributes to illuminate an overall research question. In the integration and interpretation of results, it can be chosen to weight e.g. the quantitative results over the qualitative, or equal weight can be given to the different methodologies (98,99).

In this thesis, the quantitative and qualitative paradigms are weighted equally. Furthermore, the literature on mixed-methods design offers different suggestions on how to integrate and interpret the results (98,99). Inspired by O’Cathain (99), I have sought to integrate the studies throughout the research process, and thus, I aimed at integration through design, methods, interpretation and reporting. In the following, I give an overview of the different forms of integration applied.

### **Epistemological and ontological approaches**

A mixed-methods design offers the possibility to study one or more related questions from several angles, it rejects dogmatism and the long-standing dispute between quantitative and qualitative designs (100). At the centre of the mixed-methods approach stands the research question; and by abstaining from methodological dogmatism the researcher can choose the design best fit for a given question. By doing so, the research design includes a pluralist approach, and this thesis rests on a pragmatist and pluralist understanding of the scientific inquiry as explained below.

#### *Pragmatism*

My understanding of pragmatism relates to C.S. Peirce (101) and John Dewey (102).

Pragmatism fits well with the mixed-methods design in that it rejects traditional dualisms such as objectivism vs. subjectivism, it recognizes the existence of a physical world, as well as a social world, and the fact that knowledge can both be based on the reality of the world and constructed. Beliefs and theories are seldom complete or absolute, but will, and should be, challenged (so-called fallibilism); and we must live by the pragmatic truth, the one we are able to obtain, while we acknowledge that there might be a different final truth, one that is standing at the end of the days (100–102). Pragmatism is also value-based and endorses the practical real-life consequences of research, prioritize practice over philosophy, and advocate for shared values such as democracy, freedom and equality (100).

#### *Pluralism*

Pluralism in science implies by definition a lack of consensus, and the fact that there might be a multiplicity of scientific hypotheses and research designs around a certain question. Johansson and Lynøe claim that pluralism can be either acceptive or competitive (103). Social constructivism represents an acceptive pluralism with the view that knowledge is a social

construct, and no final truth exists. In contrast, prototypical positivism with the view that only one truth exists, implies the rejection of any kind of pluralism. Finally, a competitive pluralism implies accepting that, even though a theory or finding may appear true, it might in principle be wrong; and this way of doing science implies having a *‘epistemologically split vision on truth’* (103). A fallibilistic approach, as described by Peirce (101), represents this understanding that no knowledge claim, even one that is true, can be proved beyond doubt. This leads me to the ontological nature of quantitative and qualitative data, claiming that even though some level of dichotomy between the applied quantitative and qualitative methods might exist, it is often exaggerated. Pure quantitative data probably merely exist in mathematics. Most other disciplines, traditionally labelled as quantitative, include some kind of qualitative features. The included register- and survey data in this thesis are quantifications of qualitative features such as ‘an encounter between a nurse and an IHD-patient’. That is, register data are quantifications of qualitative data; and in the wordings of Johansson and Lynø: *“the ordinary opposition between ‘qualities’ and ‘quantities’ is at bottom an opposition between ‘qualities’ that cannot be quantified and ‘qualities’ that can be turned into ‘quantities’”* (103).

#### **Access to care and the Tanahashi framework for effective coverage of healthcare**

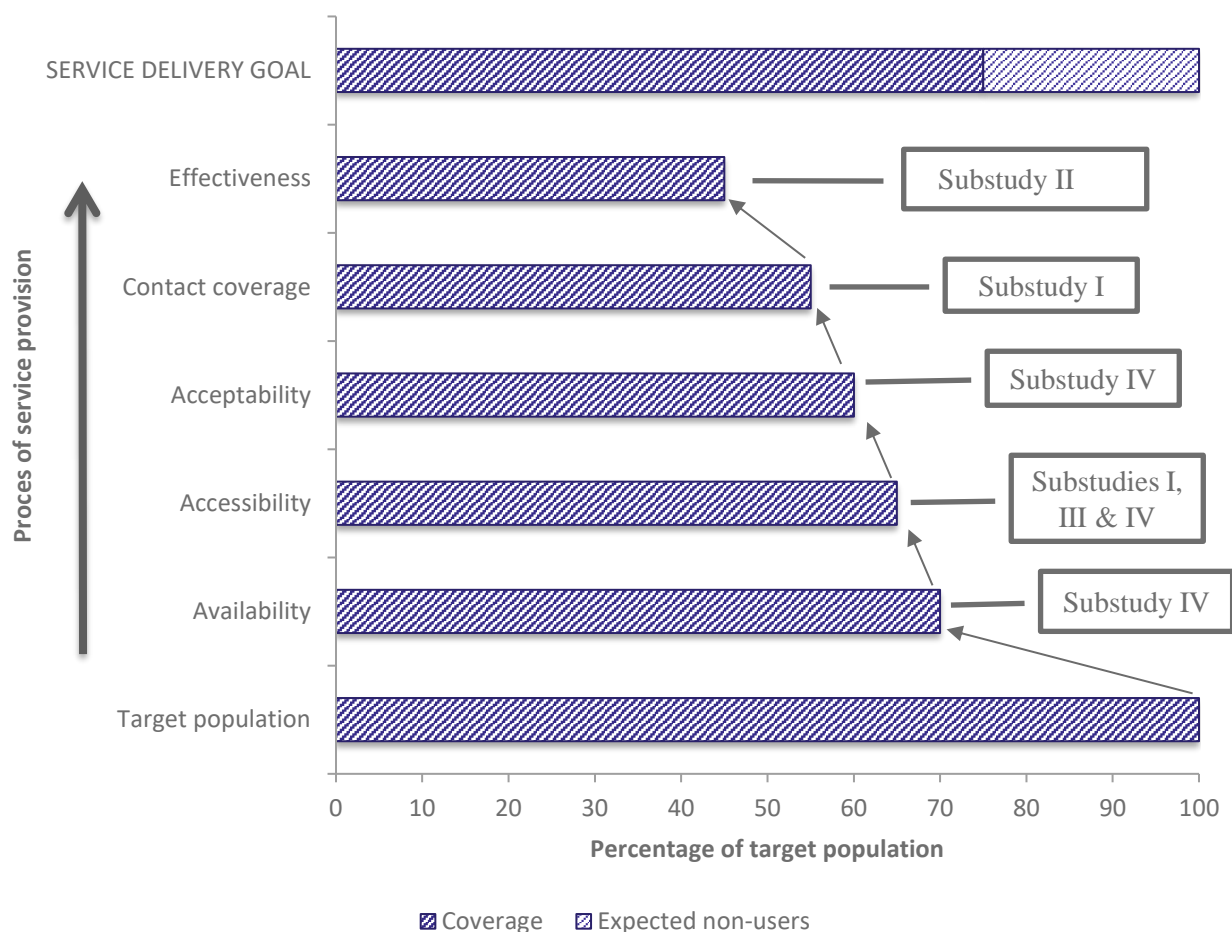
Access in this thesis is defined as the opportunity or ease with which users are able to reach and obtain appropriate services in proportion with their needs (104). The concept is further divided into realised access, defined as the proportion of potential users who use the healthcare service; and effective access, defined as the proportion of users who experience effect of the use, according to predefined indicators. I evaluate access by applying the Tanahashi framework for effective coverage of healthcare (10). The framework operates with the five domains of availability, accessibility, acceptability, contact coverage and effectiveness of healthcare; and effective coverage is used equivalent to the concept of effective access. Access is often related to the concepts of equality and equity, and studies on minorities tend to have a comparative approach in which the majority population is used as comparison, usually with the aim of identifying possible inequalities or inequities. The concept of inequity refers to an unfairness of the observed differences, where use does not reflect the health needs, whereas inequality merely describes differences in use (105). In this thesis, I apply a comparative design in substudy I, and partially in substudy II, whereas substudies III and IV are without comparison groups. I have

chosen to use the concept of equality because comparisons in substudies I and II cannot give firm answers to the needs of the studied population groups.

By ways of discussing the findings according to the domains of the Tanahashi framework for effective coverage of healthcare (**figure 2**), I shall be able to situate the thesis in the literature on access to health, and the use of an overarching framework allows me to integrate findings of the substudies (10). Furthermore, the framework can be used as a tool to identify possible bottlenecks in migrants' access to cardiac rehabilitation in a Nordic welfare state, and thus it facilitates the transmission of research findings into practice guidelines (9,106). In the following, I provide a description of the historical background of the Tanahashi framework and situate it within the literature on the right to health and access to healthcare.

The Tanahashi framework from 1978 is a precursor of the AAAQ framework, referring to the domains of availability, accessibility, acceptability and quality that are integrated into the UN General Comment No. 14 on The Right to the Highest Attainable Standard of Health (13). The Tanahashi framework diverges slightly from the AAAQ framework in that quality is not included as a separate domain in the Tanahashi framework, but is instead a cross-cutting feature, underpinning necessary features of the other domains. During my research, I have not identified explanations to the transition from five to four domains or the replacement of the contact coverage and effectiveness domains with a quality domain. Ultimately, I have chosen to apply the five domains of the Tanahashi framework since it is more explicit in the differentiation between the share of the target population who use the service (contact coverage) and the share of the target population for whom the service is effective (effectiveness). **Figure 2** illustrates the process of service provision and how this determines the goal of effective coverage of healthcare (9,10). Below follows a short overview of the five domains with an emphasis on possible barriers and enablers relevant for migrants living in a welfare state.

**Figure 2. The Tanahashi framework for effective coverage**



Source: Tanahashi 1978 (10)

### *Availability*

The availability domain includes aspects of the resources available. Nordic welfare states are, in a global perspective, capable of allocating substantial financial resources for healthcare, and has a high density of health professionals. However, healthcare systems in Nordic welfare states are under pressure due to increasing expenditures to medications and an increasing number of elderly people. Lack of availability of healthcare, e.g. difficulties in recruitment of doctors in deprived or remote areas, may therefore be on its rise.

### *Accessibility*

The accessibility domain includes four overlapping subdomains: 1) physical accessibility, such as proximity and availability of transport; 2) economic accessibility, such as out-of-pocket payment; 3) information and organizational accessibility, such as opening hours, appropriate information on health topics and access to interpretation; and 4) discrimination linked to gender or ethnicity.

### *Acceptability*

The acceptability domain includes barriers and enablers related to diversity sensitiveness and medical ethics. Health services and providers must be respectful and sensitive to the individual and act according to ethical guidelines. This includes paying attention to the culture- and gender-specific needs of minorities, protection of confidentiality, avoidance of stigma and other stereotyping or discriminatory behaviour.

### *Contact coverage*

Contact coverage is defined as the ratio of people who have been in contact with the healthcare service divided by the size of the target population. In this thesis I assess both contacts for CR-services and use of preventive medications. Hence, I also apply the concept of contact coverage to the assessment of use of preventive medications and define it as the ratio of people who use medications divided by number of people in the target population.

### *Effectiveness*

Effective coverage is defined as the ratio of people who have received effective care, divided by the size of the target population. We need to evaluate the effectiveness domain because contact with healthcare does not necessarily imply the improvement or solution of the health problem in scope, which is the final goal of effective coverage. Criteria for the assessment of effectiveness should be inclusive for the specific needs of the population in focus. E.g. effectiveness of interventions aiming at behavioural changes may differ among migrant populations and local-born and criteria must be adapted according to this.



## Material and methods

### **Do migrant patients, diagnosed with ACS, differ from Danish patients in their use of CR, and what role do sociodemographic factors and comorbidity play in use? (Substudy I)**

**Objective:** To test the hypothesis that migrants to Denmark, compared to Danish-born patients, show lower use of preventive medications, physical exercise, dietary advice and patient education after ACS, and to control for confounding by comorbidity, sociodemographic factors and whether patients were discharged from a university-affiliated hospital.

**Design:** Nationwide register-based follow-up study

**Study population:** We used data from the Danish National Patient Register (NPR) to identify subjects discharged with ACS during the period 1.1.2010 to 31.12.2013. NPR contains information on discharge diagnoses, hospital, hospital-based activities such as physiotherapy and day of discharge for in- and outpatients. Data on death, age and sex were retrieved from the Central Person Register (CPR). The study population (N=33.199) was linked to registers at Statistics Denmark containing information on country of origin and sociodemographic variables. The population was classified as Danish-born (n = 30,686) versus non-Western (n = 1631) or Western (n=882) migrants. We divided non-Western migrants into subgroups at the country level and compared Danish-born with the three largest such subgroups, namely Turks (n = 363), nationals from the former Republic of Yugoslavia (n = 291) and Pakistanis (n = 193).

**Data collection:** Data on reimbursed prescriptions were retrieved from the Register of Medicinal Products Statistics and included statins (C10A), ADP-inhibitors (B01AC04, B01AC22, and B01AC24),  $\beta$ -blockers (C07) and ACE-inhibitors (C09). Data on physical exercise, dietary advice and patient education were retrieved from NPR. Statistics Denmark provided data on the covariates family income, education, employment and cohabiting status, and NPR on comorbidity and whether non-pharmacological secondary prevention interventions were delivered by university hospitals.

**Analysis:** Outcomes were i) initiation of preventive medications, ii) initiation of physical exercise, dietary advice and patient education, iii) time to discontinuation of preventive medications, and iv) number of contacts for physical exercise, dietary advice and patient education. Initiation of medications was defined as subjects having claimed reimbursement of at least one prescription within the 180-days observational period. Discontinuation of medications

was defined as failing to claim reimbursement of a new prescription within 90 days after estimated date of expiry of a reimbursed prescription. Initiation of physical exercise, dietary advice and patient education was defined as having at least one contact per type of intervention. In addition, the number of contacts for physical exercise, dietary advice and patient education was determined with a follow-up period of 180 days from the date of discharge. All outcomes, except number of contacts for physical exercise, dietary advice and patient education were adjusted for age, sex, comorbidity, family income, education, employment, cohabiting status, and whether discharged from a university-affiliated hospital.

### **Is participation in patient education associated with higher medication persistence among ACS patients in general as well as among the subgroup of patients with a migrant background? (Substudy II)**

**Objective:** To test the hypothesis that participation in patient education is associated with higher medication persistence among ACS patients in general, as well as among the subgroup of patients with a migrant background.

**Design:** Nationwide register-based follow-up study

**Study population and data collection:** The study population and data sources were the same as used in substudy I, except that there was no division into subgroups at country-level.

**Analysis:** Danish national clinical guidelines recommend patient education after ACS to include education about the disease, symptoms, risk factors, prevention, medications, screening of mental health status and psychosocial counselling. Furthermore, it is recommended to structure patient education into one introductory session, the actual patient education programme, and a final individual session. Therefore, patients who had  $\geq 3$  contacts were likely to have completed at least parts of the patient education programme, and the cut-offs were determined according to this (cut-offs at 0, 1-2, and  $\geq 3$  contacts). Hence, subjects were divided into three groups according to their number of individual contacts; and initiation and discontinuation of medications were evaluated for the entire population and stratified according to migrant status. In order to assess whether migrant status was an effect modifier in the association between patient education and medication persistence we used Wald's tests to determine whether the effectiveness of patient education differed significantly according to migrant status. Results were

presented as crude and adjusted by multivariable analyses, with the inclusion of all covariates as potential confounders.

### **Do migrants have access to CR services; and are interpreter services and multilingual materials provided at hospitals and in municipalities? (Substudy III)**

**Objective:** To examine whether there are barriers to access to CR for migrants, with a specific focus on migrants who speak little or no Danish.

**Design:** Nation-wide surveys

**Study population:** Respondents were health professionals (physicians, nurses, dietitians and physiotherapists) engaged in the provision of CR at hospitals and in municipalities.

**Data collection:** The surveys were conducted in 2013 and 2015 as parts of the data collection for the Danish National Cardiac Rehabilitation Database. Information on availability of exercise training, patient education, psychosocial support, smoking cessation support, nutritional counselling was collected by way of parallel web-based questionnaires sent out to all hospitals offering CR services (n=35) and all Danish municipalities (n=98). The survey from 2015 contained additional questions about socially differentiated CR; and those who provided socially differentiated CR programmes (hospitals: n=19/35, 54%, municipalities: n=31/71, 44%) responded additional questions on the provision of interpreter services and multilingual information material. Respondents were given the opportunity to elaborate on their experiences in open-ended answers.

**Analysis:** Substudy III provided a descriptive analysis of barriers to access, including the reporting of frequencies. Furthermore, factors that could potentially predict the provision of interpreter services and multilingual material were assessed. For hospitals data, variables applied were hospital type and percentage of migrants in a hospital's catchment area. Municipality data variables were percentage of migrants in the municipality and population size.

## **How do Turkish and Pakistani migrants experience everyday life with IHD, how does CR support the achievement of good health, and what are the experienced barriers and enablers for use of CR? (Substudy IV)**

**Objective:** To explore how Turkish and Pakistani migrants experienced everyday life with CR, how CR supported the achievement of good health, and to explore experienced barriers and enablers for use of CR.

**Design:** Explorative interview study

**Study sample:** Seven households, including 16 persons of Turkish or Pakistani origin. One member of the household had a recent CVD-diagnosis. The gender distribution was unequal, with six men and one woman among interviewees with a CVD-diagnosis. Interview-candidates were identified during the year 2017 through patient files from three outpatient clinics providing CR. We aimed at equal distribution of interviewees originating from Turkey and Pakistan and men and women, and maximum variation of age and adherence to the CR-programme.

Interviewees were included until saturation was reached. Our aim of equal gender-distribution could not be met. Out of the 31 potential candidates, only five were female, one was on a long-term family-visit in her country of origin, two refused participation, and one could not be reached through available contact information

**Data generation:** Guided interviews were conducted in interviewees' homes, focusing on everyday life, disease management and experienced barriers and enablers for use of CR-services. Five of the seven interviews were conducted with the aid of a professional interpreter.

**Analysis:** The recorded interviews were transcribed, and where interpreter had been used, conversations between interviewee and interpreter were back-translated into Danish. Data were analysed by thematic network analysis, as described by Attride-Stirling (107). Initially, data was approached abductively (108), which generated the hypothesis that perceived identity is central in disease management. Consequently, a more deductive approach was taken, and data was analysed through the lens of Leventhal's Common-Sense Model of Self-Regulation (CSM) (109). The model offers a framework for describing underlying mechanisms related to health seeking behaviour and disease-management for both acute and chronic conditions.

# Results

The overall objective of gaining insight into access to CR for migrants with IHD, and into experiences with being a migrant patient in the intersection between different parts of the healthcare system was covered by the four substudies.

**Substudy I** addressed the realised access in terms of use of preventive medications, physical exercise, dietary advice and patient education. **Substudy II** addressed effective access by assessing associations between use of patient education and the subsequent medication persistence, and whether the association was equally strong among migrants and local-born.

**Substudy III** addressed the role of interpreter services and multilingual information material in access; and access to CR was addressed in **substudy IV** from the perspective of the migrants.

The aim of gaining insight into experiences with being a migrant in the intersection between different parts of the healthcare system was mainly addressed by the qualitative **substudy IV**, but **substudy III** also addressed this by evaluating system-related language barriers in both municipalities and hospitals.

The research questions were addressed substudy by substudy, as described in the following:

## **Substudy I: Do migrant patients, diagnosed with ACS, differ from Danish patients in their use of CR, and what role do sociodemographic factors and comorbidity play in use?**

**Substudy I** addressed migrants' use of CR by comparing use of preventive medications, physical exercise, dietary advice and patient education among Western and non-Western migrants with Danish-born as reference. Furthermore, use of the abovementioned interventions was compared between Danish-born and the subgroups of migrants from Turkey, the former Republic of Yugoslavia, and Pakistan. All results were adjusted for comorbidity, sociodemographic factors and discharge from university-affiliated hospitals.

The study found significant differences between non-Western migrants and Danish-born, but not between Western migrants and Danish-born. Non-Western migrants were relatively less likely to initiate ADP- and ACE-inhibitors (RR: 0.93, 95% CI: 0.90; 0.96 and 0.91, 95% CI: 0.87; 0.96); and they had higher risks of discontinuation of all medication groups (Statins: 1.64, 95 % CI: 1.45; 1.86, ADP-inhibitors: 1.72, 95% CI: 1.50; 1.97,  $\beta$ -blockers: 1.52, 95% CI: 1.40; 1.64, and ACE-inhibitors: 1.72, 95% CI: 1.46; 2.02). Similar patterns were found among the Turkish,

former Yugoslav, and Pakistani subgroups with adjusted HR ranging from 1.28 (1.07;1.53) to 2.70 (1.89;3.85).

For non-pharmacological interventions, the initiation of patient education was less likely among non-Western migrants compared to Danish-born (RR: 0.95, 95% CI: 0.92; 0.98). Among subgroups, differences tended to be attenuated, especially in the Turkish subgroup, which was less likely to initiate physical exercise, dietary advice and patient education (RR: 0.83, 95 % CI: 0.73;0.94, 0.80, 95% CI: 0.68; 0.95 and 0.90, 95% CI: 0.84; 0.97). The assessment of total number of contacts for physical exercise, dietary advice and patient education showed that non-Western migrants had significantly fewer contacts for physical exercise when compared to Danish-born (median 7 vs. 9,  $p < 0.001$ ). Furthermore, Western and non-Western migrants had statistically significant fewer contacts for patient education when compared to Danish-born, although the median number of contacts were similar (median 4 vs. 4,  $p = 0.036$  and median 4 vs. 4,  $p = 0.011$ ). Among subgroups, former Yugoslavs and Pakistanis had fewer contacts for physical exercise (median 9 vs. 5,  $p < 0.001$  and median 9 vs. 4,  $p < 0.001$ ), and Turks showed a probability of fewer contacts for physical exercise close to the significant cut-off point of 0.05 (median 9 vs. 8,  $p = 0.051$ ). Former Yugoslavs had fewer contacts for dietary advice (median 1 vs. 2,  $p = 0.006$ ), and fewer contacts for patient education were observed among Turks (median 4 vs. 3,  $p = 0.029$ ) and Pakistanis (median 4 vs. 3,  $p = 0.040$ ).

Finally, confounding by comorbidity, whether discharging hospital was university-affiliated, and the sociodemographic factors income, education, occupation or cohabitation, was evaluated. The study showed limited confounding, indicating that these factors were not major barriers to CR.

### **Substudy II: Is participation in patient education associated with higher medication persistence among ACS patients in general, as well as among the subgroup of patients with a migrant background?**

*Substudy II* addressed the effectiveness of patient education in relation to medication persistence, and whether associations were modified by migrant background. It is important to notice that the study assesses associations and does not give any firm answers to causal inferences.

The study showed that patient education was associated with higher initiation of preventive medication. In the entire study-population, adjusted RRs ranged from 1.15 (95% CI: 1.14; 1.17) for those with 1-2 contacts to 1.30 (95% CI: 1.27; 1.33) for those with  $\geq 3$  contacts. When stratifying according to migrant status, most associations persisted and Wald's test for effect

modification according to migrant status showed significantly stronger effect in migrants for initiation of ADP-inhibitors (adjusted RR 1.28, 1.37, 1.39,  $p=0.002$ ). Contrastingly, effect on initiation of statins was weaker according to migrant status in subjects with 1-2 contacts (adjusted RRs: 1.15, 1.12, 1.07,  $p=0.04$ ).

Associations between patient education and discontinuation of preventive medications were found only for some medication groups. In the entire study population,  $>3$  contacts was associated with lower risk of discontinuing statins (0.86, 95% CI: 0.79;0.92), beta-blockers (0.92, 95% CI: 0.88;0.97) and ACE-inhibitors (0.89, 95% CI: 0.80;0.98). Similar patterns were found when stratifying according to migrant status. No significant effect modifications by migrant status (Wald's test) were observed for discontinuation, i.e.  $p$ -values ranged from 0.26 – 0.97. Finally, there were indications on a dose-response relationship with the strongest associations among subjects with  $\geq 3$  contacts.

### **Substudy III: Do migrants have access to CR services, and are interpreter services and multilingual materials provided at hospitals and in municipalities?**

*Substudy III* addressed the role of language barriers in the provision of CR. Among included municipalities, 84 % ( $n=26/31$ ) offered interpretation services, and only one (3% ( $n=1/31$ )) provided multilingual information material. There appeared to be fewer language barriers at hospitals, with 100 % ( $n=19/19$ ) providing interpreter services and 32% ( $n=6/19$ ) providing multilingual information material. This finding was contrasted by open-ended answers given by hospital-based respondents, who endorsed that municipalities had customized offers for non-Danish speaking patients. Therefore, particularly non-Danish speaking patients were referred to the municipality. Lastly, health professionals in charge of CR were asked if they considered specific patient-categories as vulnerable in the CR-trajectory. Among hospital-based health professionals 84 % ( $n=16/19$ ) considered non-Danish speaking patients as vulnerable, against 61% ( $n=19/31$ ) in municipalities. These ratios were comparable to the ratios for other patient categories, such as those with low education, alcohol or drug abuse, psychiatric disorder, and limited social network.

#### **Substudy IV: How do Turkish and Pakistani migrants experience everyday life with IHD, how does CR support the achievement of good health, and what are the experienced barriers and enablers for use of CR?**

*Substudy IV* took an explorative approach to Turkish and Pakistani migrants' experiences with everyday life with IHD, experienced support by CR to the achievement of good health, and experienced barriers and enablers for use of CR. The global theme 'Redefining the self between illness and belongingness' was derived from the four organizing themes I) Deviations of the usual normative self: "My life kind of stopped", II) Action plans: "After those twelve weeks there is just the medicine", III) Embedded routines: "You cannot change it all – we grew up with it", and IV) Access to healthcare: Relatives as interpreters of disease representations.

I) The usual normative self conflicted with physical and social consequences of IHD and challenged the individual's role in the family and society, and thus, the experienced social belongingness. Illness representations were therefore related to major life-crises. II) The conflicts between the usual perceived self and representations of illness were coped with in different ways; by avoidance of illness representations, e.g. non-adherence to medications, or by prioritizing routines that reinforced social belongingness over routines to prevent a potential future health threat. Consequently, action plans, as provided in CR, were experienced as not being useful if they failed to take the social and cultural context into consideration. III) In order to be useful, CR services therefore needed to be more attentive towards the migrant's everyday life, including their cultural and social routines, norms and taste. IV) Relatives' help as interpreters, not only of language, but also of the migrant's way of expressing symptoms of IHD, were crucial for accessing healthcare services because of the migrants' difficulties with convincing health professionals about their need for care and hospitalization. Furthermore, brief telephone hours in municipalities and referral letters written in Danish only were barriers to access in the inter-sectorial transitions from hospitals to municipality-based CR, and some had to rely on the help from relatives who were more fluent in Danish. Financial barriers were specific to the use of preventive medications and to the sustainment of physical exercise after the twelve-week exercise programme had been completed. Lastly, musculoskeletal comorbidities in the forms of pain and immobilization were also described as accessibility barriers.



# Discussion

In the following, I set out by discussing the material and methods, including general issues of the applied categorizations, my use of mixed-methods and the different methodologies used in the substudies. Subsequently, principal results are discussed in the light of existing literature.

## Discussion of materials and methods

### Ethical and methodological implications of categorizations in migrant and ethnicity research

The substudies operated with different subgroups of migrants. *Substudies I and II* used the categories Western- and non-Western migrants and *substudy I* divided further into the three most frequent countries of origin of the non-Western migrant group (Turkey, the former Republic of Yugoslavia and Pakistan). *Substudy III* focused on migrants who are non-Danish speaking; and *substudy IV* focused on migrants of Turkish and Pakistani origin.

It is important to be aware of the implications of the categorizations made in research. They affect, not only the findings and conclusions of the single study, but may also affect future hypotheses and theories. Perhaps even more important, categorizations of groups and individuals are formative and shape understandings and perceptions of identities both in society and at the individual level; and therefore categorization choices call for ethical considerations (110).

There is no gold standard for categorizations in migrant and ethnic minority research; and the comparison of studies on migrants and ethnic minorities is a continuous challenge (53,110,111). Common concepts of the population in scope are migrants (including immigrants and emigrants), ethnicity, race, and country or region of birth. There are assets and weaknesses to the different categorization choices which must rest upon considerations of the available data, ethics, scope of the research, and layperson and scientific understandings of the concepts. The concepts emphasize different features, are overlapping and assigned by society rather than by nature (110). In his work on classifications within migration, ethnicity and health research, Bhopal defines ethnicity as "*the group a person belongs to as a result of a mix of cultural factors, including language, diet, religion and ancestry*" (110). Race is a controversial concept in that the significance of biological factors cannot explain most inequalities in health among racial groups. The migrant category has been defined by the life event of moving away from one's habitual place of residence (14,110). Albeit there are several overlaps of the categories, the migrant category does, in theory, not include assumptions on cultural identities within the group; and it

does not include descendants, unless otherwise stated. However, in the dissemination of this thesis I am aware that the postulation that the migrant category does not include assumptions of cultural identities is unlikely to reflect the common layperson-understanding of the category. In particular, since the category in recent years has been used as a concept, mainly including migrants who migrate from non-Western to Western countries in search for better economic prospects, as opposed to refugees who migrate on the grounds of war or individual persecution (112).

Inspired by previous works on migrant and ethnic minority health (22,111,113,114), I wanted to avoid accentuation of cultural differences which could direct the gaze away from phenomena explained by the unique life-event that migrants with IHD find themselves in, and which may be idiosyncratic once we understand the life-story and everyday life of the individual (114). The choice of working with the migrant category was thus based both on this specific research interest in the contribution by the migration history, and on the pragmatic considerations that Danish registers include information on country of birth, but not on ethnicity. As explained in the background section, country of birth may be a weak proxy for ethnicity because each country may include many different ethnic groups. Albeit country of birth is also a proxy for migration, I consider it more precise to use the migrant concept to describe a group categorized according to the individual being born outside of Denmark by non-Danish parents.

I chose to subdivide migrants into Western and non-Western migrants according to categorizations used by Statistics Denmark (15). These categories are used in much research and grey literature on migrants in Denmark which facilitates comparison of results at the national level. The Western/non-Western categories can be criticized for an overly homogeneous representation of heterogeneous subgroups, including countries from many different regions and individuals with diverse reasons for migrating. I attempted to address this by subdividing into country of birth wherever applicable. In substudy I, the Turkish, former Yugoslav and Pakistani subgroups were included. In substudy IV, I chose to include only interviewees of Turkish and Pakistani origin. In qualitative interview studies, narrow and well-defined inclusion criteria are desirable for the trustworthiness of the study (115), and I chose these specific groups because they are among the largest migrant groups in Denmark, which gave me easier access to study participants. Furthermore, the Turkish and Pakistani labour migrants have comparable migration histories, and commonalities in the sample might highlight interesting deviations which can lead to new and surprising findings (116).

### **The mixed-methods approach**

There have been several attempts to systematize quality criteria of mixed-methods research, albeit it is also recognized, that these criteria are not much different from what also applies to the quantitative or qualitative methods included (117,118). In general, what should stand in focus in mixed-methods design is the research problem and what was done to address it (117–120).

O’Cathain has suggested a framework for the quality assessment of mixed-method design with the following five criteria (121): i) Justification for the mixed-methods design should be clear, ii) the overall design should be described, including purpose, priority and sequence of each of the applied methods, iii) each method should be described with rigour, iv) there should be an integration of the substudies, and v) limitations and insights gained from applying the mixed-methods design should be described.

Firstly, I chose a mixed-methods design because the overall objective of the thesis includes quantitative as well as qualitative characteristics. Furthermore, the mixed-methods design allowed for multiple perspectives on access to CR; and by approaching the question quantitatively from the system-side (substudy III) as well as qualitatively the patient-side (substudy IV) I was able to gain a broader understanding of the realised (substudy I) and effective access (substudy II). I sought to be explicit about the philosophical and theoretical position of the mixed-methods approach by describing the pragmatic and pluralist approach in the background section. Hereby, I integrated the differential research methods into a philosophical position, recognizing that knowledge can be based on the reality of the physical world and on the constructed social world (100–102). A long-standing debate in philosophy of science has been that of quantitative versus qualitative methods and claimed problems with the epistemological and ontological features of the approaches. The methods have been dichotomized into either/or, with quantitative methods being ascribed to objectivity, counting, and pretty sure data, but with a risk of reductionism, and qualitative methods being ascribed to subjective interpretations, and not being able to produce secure data (103). However, the combination of quantitative and qualitative methods is feasible and sensible but requires clarity in epistemological and ontological understandings. In a pragmatic perspective, all knowledge implies some kind of interpretation and no clear-cut distinctions between objective knowledge and subjective interpretation exist. Moreover, there are no indications that knowledge based on quantitative data, as e.g. register data, is truer than knowledge based on qualitative data as e.g. interviews. Finally, the fact that pragmatism is value-based and endorses the practical real-life

consequences of research is a feature that fits well with the justifications for applying a mixed-methods design (100).

The second of O’Cathain’s quality criterion is that of clarity of the purpose, priority and sequence of the included methods. Above, the justifications and purposes for choosing the differential methods have been described. I chose to weight the methods equally; and timing of the studies were planned in a way that has been described as an explanatory sequential design, which is characterized by initial quantitative study designs, followed by a qualitative design in order to further explore the findings (98). There was a temporal order of the studies; starting out with the register studies (substudies I and II), followed by a survey study (substudy III) and finally a more explorative qualitative study (substudy IV) was conducted.

The third criterion is that the differential quality criteria for the included methods should be followed with transparency, consistency and rigour. This criterion is addressed in the below sections where the methods of each of the substudies are discussed.

The fourth criterion is that of integration of the substudies. Integration of data at the *methods* level took place as results from one or more studies informed the research questions of subsequent studies. Fetters et al. define this kind of linking of data collection and analysis as *building* (98). The primary goal of *substudy I* was to investigate the overall question of use of cardiac rehabilitation from a comparative approach and clarify possible inequalities and confounding factors. The design of *substudy II* was based on the results from substudy I, in which migrants were found to have lower use of patient education and lower use of preventive medications. I therefore chose to assess whether use of patient education was associated with subsequent higher persistence with preventive medications in the entire study population, and among the subgroup with a migrant background. The design of *substudy III* was guided by findings from substudy I, and assessed the hypothesis that there were system-related access barriers to cardiac rehabilitation among non-Danish speaking migrants. Lastly, substudies I, II and III informed the inclusion strategy, the interview guide and the analytic process of *substudy IV*, where I wished to explore migrant patients’ experiences with cardiac rehabilitation and everyday life.

Integration at the *interpretation* and *reporting* levels will be presented as a narrative integration under the section on discussion of the results of the four substudies. The results will be discussed through the lens of the Tanahashi framework because it captures the overall objective of gaining insight into effective access to CR and in patients’ experiences with CR (10). The discussion of

results according to the different domains of the framework also gave me the opportunity to assess coherence of the different substudies, e.g. to evaluate if there were any contradictory findings, if findings supported each other, and if some findings could explain or expand my understanding of other findings. An expansion of understanding could for example occur when different or complementary aspects of a single phenomenon are described. As explained by Fetters et al.: *“Quantitative data may speak to the strength of associations while qualitative data may speak to the nature of those associations”* (98). Furthermore, principal findings are presented jointly in appendix (#), inspired by O’Cathain, Murphy and Nicholl (99). This presentation also provided an overview of the population groups in focus in the substudies.

### **The register studies**

Methodological strengths and weaknesses of substudies I and II relate to i) the size of the population (N=33.199), ii) the low risk of selection bias and precise estimate of the target population, iii) the assessment of both pharmacological and non-pharmacological measures in a nation-wide population, and iv) the adjustment for possible confounding factors.

i) The Danish registers offer excellent possibilities for research at the population-level and data quality is high (122,123). However, administrative registers are not purposely designed for research; and the primary objective of the NPR is administration, e.g. clinical departments are paid for services according to diagnose registration groups (DRG) reported to the NPR and reimbursement differs according to categorizations defined by the National eHealth Authority. Therefore, it has been hypothesized that there is a risk of bias caused by the DRG-creep phenomenon, where clinicians are thought to have incentives to be most thorough with registrations of DRG codes with the highest reimbursements (124).

ii) Previous literature on migrants’ access to healthcare in the context of a welfare state has discussed the extent to which realized access to healthcare reflects actual health needs of migrant populations (125,126). An asset of the focus in substudies I and II on ACS-patients’ use of healthcare, in a one-string healthcare system like the Danish, is that the ratio between healthcare needs and realized access is very close to one. Patients encountering an incident of ACS are quite certain to be hospitalized for the severe incident, unless they die. Furthermore, albeit diagnostic misclassification is an issue in international literature on incidence and prevalence of cardiologic diseases (35), Danish studies have found predictive values of the ACS-diagnosis in NPR to be valid (127,128).

iii) Substudies I and II assessed both use of preventive medications and non-pharmacological interventions. Previous studies have examined either pharmacological or non-pharmacological preventions, but the assessment of both preventive measures in the same large nationwide population is new. However, there are also weaknesses that must be addressed: Physical exercise, dietary intervention and patient education assessed in substudies I and II only included hospital-based services, but the interventions are also provided in municipalities, for which we have no register data. Thus, in the case that there are between-group differences in referral to municipality-based services, this would bias our findings.

iv) Results in substudies I and II were adjusted for comorbidity, socio-demography and university-affiliation by discharge hospitals, and I hereby aimed at isolating the effect of migrant background from other possible explanations to inequality in use. However, the adjustment by sociodemographic status introduced some weaknesses to the study. The education variable was categorized according to the international standards of education (129), but migrants with educations obtained in the country of origin are often misclassified in Danish registers, as having no education. Furthermore, information on education was missing for a relatively high number of migrants (Missing: Danish-born: n=1474, 4.8%; Western: n=130, 14.7%; non-Western: n=255, 15.6%). This weakness was addressed by Statistics Denmark in 2017 with a survey among a representative sample of migrants assessing educational levels obtained abroad (130). The extrapolation of survey-results to the entire migrant population led to substantial adjustments of estimated educational levels. It was found that 19.9% of migrants previously categorized as having no secondary or tertiary education had a tertiary education. This new variable was released after the termination of our analyses and we have used the former variable. It is therefore possible that more exact categorizations of educational levels might have led to adjustment of the conclusion of limited confounding by education. It should, however, be noted that there is an age- and social gradient in prevalence of cardiac diseases, and therefore frequencies from the new education variable are not directly comparable with those of substudies I and II. Other studies have investigated the effect of sociodemographic factors among migrants, and a Dutch study found varying effects of education and occupation on the occurrence of CVD risk factors across ethnic groups (38), and another study found that the sociodemographic gradient tended to be flatter in migrant populations, compared to local-born (131). Family income was also included as a possible confounder in substudies I and II, and a previous Danish study have discussed its weaknesses as a proxy for socio-economy in migrants (132). However,

uniform effects of socio-demographic factors across the included groups are not prerequisites for taking them into account, and it is important to perform studies with the inclusion of possible confounders in our efforts to disentangle the effect of migration. Weak sociodemographic proxies call for cautious interpretations, and therefore I do not give firm conclusions on the effect of sociodemographic factors, and it is possible that the appliance of other proxies for education and income would have shown some confounding.

Specifically, for substudy II, it must be stressed, that the study assesses associations, and no definite conclusions on causal inferences can be made. Three types of confounders may have played a role in our findings; i) confounding by health seeking behaviour, suggesting that patients who are persistent with their medications are more likely to engage in preventive health services like patient education, ii) confounding by health status, where physical or cognitive functioning affects both medication persistence and use of preventive health services, and iii) confounding by provider, suggesting that some doctors may be more likely to prescribe medications to patients that are engaging in preventive health services. The observational design and available data did not allow for an exclusion of these possible confounders. A randomised experimental design could remove the risk but might instead introduce selection bias. Therefore, an important contribution by this study is the provision of knowledge based on an unselected population.

### **The survey study**

The assessment of barriers on the provider-level is important for the disentanglement of factors contributing to the observed inequalities in use of CR-services. An important issue in survey research is that of content validity, where systematically misunderstood questions, or questions not perceived as meaningful, reduces the validity of the questionnaire. The inclusion of open-ended answer categories might give indications on such validity-problems (133). In substudy III, some of the open-ended answers indicated that respondents found it difficult to answer questions about vulnerable patients and socially differentiated programmes. Some respondents wrote that they took an individual approach to all patients and did not want to label migrants as vulnerable. Responses were too few to decide, whether such open answers were positively or negatively associated with the question on provision of socially differentiated programmes.

The strengths of substudy III relates to the survey being nationwide with the objective of providing a complete picture of the availability of CR services and of the accessibility to those services for migrants who speak little or no Danish. However, the study was flawed by an error

in the 2015-survey, which reduced the potential numbers of respondents. Instead of directing questions on provision of interpreter services and multilingual information material to all potential respondents (n=122), these questions were only directed to respondents who provided socially differentiated CR-programmes (n=50). Interpreter services should be available to all patients with limited Danish language proficiency, regardless of the availability of socially differentiated programmes, and therefore, preferably all 122 potential respondents should have answered these questions. New surveys will be conducted in 2018, in which all hospitals and municipalities will be included in questions on provision of interpreter and multilingual information material. The recurrent assessment of availability and accessibility of CR-services is planned to take place every third year and is part of the registration in Danish Cardiac Rehabilitation Database (74). Thus, feed-back to policy-makers and clinicians on developments in availability and accessibility is systematized with the prospects of revealing gaps and encourage to nation-wide provision of the CR-services that patients are legally entitled to, according to Danish law (134).

### **The qualitative study**

Substudy IV adds to our understanding of realised and effective access to CR, and of everyday life and disease management as experienced from the perspectives of migrants with recent IHD. The focus of inquiry is now shifting away from numbers and distributions towards experiences and categorizations construed by the individual. With this shift in focus, follows a shift in methodological quality criteria away from criteria concerning the representative sample, such as replicability and generalizability, and towards criteria concerned with the trustworthiness of the research. There are no gold standards on quality criteria for qualitative studies, but the widely applied criteria by Lincoln and Guba from 1985 characterize trustworthiness as the research meeting criteria for credibility, transferability, dependability and confirmability (135).

*Credibility* concerns the ‘truth’ of the findings and requires an awareness of the researcher’s preconceptions and the establishment of trust and rapport. *Transferability* concerns the extent to which other researchers can comprehend the process that led to the findings and is important for the evaluation of the applicability of the findings into other contexts. *Dependability* concerns the consistency of the findings; that while data are co-created in a unique relation between the researcher and the interviewees, they should be more than just occasional glimpses of individual experiences. *Confirmability* concerns the degree to which the findings are shaped by the interviewees rather than by the researcher’s own preconceptions or interests. Later literature has



discussed these criteria and there seems to be an agreement about the need to emphasize reflexivity as a cross-cutting feature of Lincoln and Guba's four criteria (118,136).

### *Inclusion*

My choice of including only interviewees with Turkish or Pakistani background rested on the principles that narrower inclusion criteria heighten the credibility and confirmability of the study. Qualitative studies seek to take the perspective of the insider and gain access to the categorizations and experiences according to which a concisely defined selection of people construes the world (115,137). Interviewees' shared experiences, such as those related to being a low-skilled labour migrant, stood out in the material and confirmed the interconnectedness between the life-story and disease management. In the selection of interviewees, I expected to include approximately ten households, because it is more important to work longer, and with greater care, with a few people than more superficially with many (115). The interviews turned out to be very rich and saturation was reached in the course of the sixth interview, due to which the seventh interview was confirmatory. However, a theme, on which I must abstain from drawing definite conclusion, is if the findings are unique for low-skilled labour migrants who encounter IHD, or whether they are equally prominent among non-migrants. The inclusion of Danish-born patients might have shed more light on this question. Nevertheless, I chose not to include Danish-born in substudy IV because the qualitative design is not very suitable for comparative analyses (115).

### *The interview and the interviewer's prior experience*

The richness of the interviews may relate to the establishment of trust and rapport between interviewer and interviewees (138). Contributing factors to this may be that interviewees were encouraged to tell their life-story, including their migration history, how they experienced their lives in Denmark, their work, and their family-relations. My own professional experience may also have contributed to the establishment of trust and rapport. I am an experienced nurse with several years of training in migrant health research. This provided a theoretical and tacit knowledge fundament for informed interviews, in which the unique life-situations of the low-skilled labour migrant encountering chronic illness was acknowledged and paid respect to. In the words of Holstein and Gubrium: *"The interviewer's background knowledge can sometimes be an invaluable resource for assisting respondents to explore and describe their circumstances,*

*actions, and feelings. Indeed, citing shared experience is often a useful way of providing concrete referents on which inquiries and answers can focus*” (139). The establishment of rapport opened opportunities to explore and go deeper into sensitive themes essential for the understanding of underlying mechanisms related to health seeking behaviour and disease management. While drawing on my professional background, I was also aware of the need to distinguish between the research interview and the kind of interviewing often practiced in the setting of the nursing practice. Nursing practice often have the aims of motivating to behavioural changes, where one strategy is for the interviewer to seek to unravel unspoken messages and play them back to the interviewee (140). However, this can be obtrusive to the research interview and destructive to good data because it may interrupt and distort the interviewees’ narratives and experiences (115). An example of how I distinguished between different kinds of interview strategies was an interview with a household, including a man with type II diabetes. During the interview, he told me he had stopped taking high doses of insulin without conferring it with a doctor. He intended to re-initiate within two to three weeks, but I knew that this could seriously damage his health and increase his risks of sequelae such as blindness or further heart attacks. However, I chose not to share these considerations with him during the interview but stayed focused on his experiences and the meanings he attributed to them. However, there was an ethical dimension to this (141) and at the end of the research interview I turned off the recording machine and asked the family if we could talk about certain things that had come up during the interview. Since they had only consented to participate in the research interview, I emphasized that they should let me know if they wanted me to stop. We then had a conversation on risks and biomedical consequences where I used the communication skills I know from motivational interviewing. Off note: The man ended up saying that, for the first time, he now understood why he should take his medications, and health professionals might benefit from putting aside our goals of motivation to life-style changes and invest more effort in listening to the patients’ stories. This is not new, but ever so important (142).

#### *Thematic network analysis and the use of an analytical framework*

Thematic network analysis, as described by Attride-Stirling, was used to analyse the interview data (107). During the initial readings and coding of the transcribed interviews, a theme related to changes of perceived identities stood out clearly. Therefore, I chose to analyse data through the lens of Leventhal’s *Common-Sense Model of Self-Regulation* (CSM) (109). The model

(appendix #) provided a theoretical framework for understanding the processes involved in illness cognition and its role in disease management. After I decided to take this analytical gaze, I re-coded data according to concepts of the model. e.g. ‘deviations of the self’, ‘illness representations’ and ‘action plans’. In many aspects, the model fitted well with data and added to my understanding of the processes involved in the individual’s disease management. However, parts of the data did not fit into the new codes and I found that I needed to supplement the CSM-inspired codes with codes related to the social context. e.g. ‘relatives’, ‘colleagues’, and ‘health professionals’. This led me to an investigation of concepts concerning the meaning of social bonds in times of illness and further on to the *sense of belonging* concept (143). The concept not only filled out the gaps I experienced in the CSM-model, but the sense of belonging concept was also helpful in broadening my understanding of why family and other social relations are so important for migrants in illness-encounters (144–146).

#### *Use of interpreters and cross-cultural interviews*

I do not speak Turkish, Kurdish, Urdu or Punjabi and had to use interpreter in five of the seven interviews. Cross-cultural interviewing and the use of interpreter represent a venue with several potential pit-falls for misinterpretations, loss, or distortions of meaning (147–151). It has therefore been suggested that a way to achieve rich and trustworthy cross-cultural interviews is to use interviewers with similar ethnic background as research participants (114). This touches upon the insider-outsider issue (151). Insiders who share ethnic backgrounds with the people in scope of the research may have the benefits of understanding cultural codes and meanings and may easier gain access and establish trust. But at the same time, insiders may have more ‘blind spots’ and may not identify and express meanings and interpretation that are tacit or regarded as idiosyncratic within the ethnic group. Outsiders may, however, find more difficulties in understanding the spoken and unspoken language, the sayings, meanings and life-situations of the individuals in scope of the research, but may easier identify categorizations and new and surprising findings (151). To some extent, the insider-outsider issue is a false dichotomy because most often research participants and researchers both fall somewhere in what has been referred to as the *borderland* in which one simultaneously belongs and does not belong (152). Another issue in cross-cultural interviewing is that of the quality of the interpretations. Albeit the use of interpreter might be experienced as a barrier in qualitative research interviews, it may have its benefits: The communication of feelings and sensitive topics is easiest in the mother tongue; and

the competent interpreter may facilitate understandings of sayings and meanings between researcher and research participant (150). Therefore, the interpreter is also a mediator of culturally informed conceptualizations and categorizations (149,150). The linguistic competencies of the interpreter are therefore vital to the trustworthiness of the study and affects both credibility and confirmability. I sought to address this issue in several ways. Firstly, I tried to identify competent interpreters. This step was not easily overcome because interpreter is not a protected title in Denmark; there is no certified education, and no control of the quality of the interpretation. I therefore had to rely on personal accounts on interpreters. I managed to identify a competent interpreter in Urdu and Punjabi but had less luck with Turkish and Kurdish interpretation. Secondly, I prepared the interpreters beforehand by informing them about the importance of objectivity, that I needed concise literal interpretation, with supplementary interpretation of cultural concepts where needed. Thirdly, all conversations between interpreter and interviewee were transcribed and back-translated into Danish by a third-person interpreter, in order to confirm or correct the oral translations.

#### *The life-story and everyday life*

The interviews were inspired by the life-story interview (116), but slightly narrower and with emphasis on the present life and interplays between the life-story, everyday life, disease management and contacts with the healthcare system. By inviting interviewees to draw a brief outline of their life-story, I wanted to hear the stories of individuals from groups who are not often heard from and to acknowledge their unique life-situation. I experienced that the approach served to build up trust and to put my own prior experiences and society's discourse on migrants in the background. I took this wide and explorative approach because I wanted to allow for the creation of new knowledge, and because I wanted to acknowledge the importance of the ways individuals categorize and situate themselves in everyday life and the meaning of this in disease management. Viruell-Fuentes have argued that migrants' formation of identity in particular needs to be understood in an expanded conceptualization as intersecting with class and gender, unfolding across the life span, and as *never complete, always in process* (153). By better understanding the present and historical situation of the migrant, meanings and categorizations may be explained by everyday life experiences and other contextual factors. In contrast, explanations emphasizing the role of culture may mask the role of the historical and social situation of the migrant (114,153).

Ethical aspects must be considered carefully in research including minority groups; and the life-story approach has emancipatory potential in that it allows for individuals or groups, who may not have a strong public voice to tell their story (116). The researcher may have the role of disseminating views and experiences from the perspective of the interviewees to society. Experiences and statements may therefore be articulated for the sake of reaching other agents than the researcher. There are different issues to consider in relation to this. Research participants may have agendas to promote, seek to emphasize their own likeability or to express gratitude, and therefore mask criticism or personal features regarded as less compelling. During the interviews, I experienced a desire from the interviewees to tell their stories. Initially, they emphasized how they had contributed to the welfare state, and how they had always been treated well by Danish healthcare professionals. However, during the course of the interviews, and with increasing rapport established, it became more prominent how they also felt helplessness, and some felt deceived by the welfare state for not providing the support they needed. Some interviewees almost demanded me to answer questions regarding experienced unfairness from the system, which can be seen as indications on the system-research participant mediator role conferred to me. These issues must be paid attention to throughout the course of the research process as they can affect the credibility of the findings; and the establishment of rapport and the researcher's reflexivity are keys to addressing these issues (116,138).

## **Discussion of results**

In this thesis, I have sought insight into access to CR for migrants with IHD and into experiences with being a migrant patient in the intersection between different parts of the healthcare system. The substudies covered different aspects of these questions, as have been presented in the results-section. In the following, results will be discussed through the lens of the Tanahashi framework for effective coverage of healthcare (10). This framing of the results allows me to integrate findings of the substudies, as described in the section on mixed-methods design, and may highlight contrasting or synergetic findings (10).

### **Availability – Substudy IV**

*Substudy IV* took an explorative approach to Turkish and Pakistani migrants' experiences with CR. Some interviewees expressed disappointment with the availability of services during rehabilitation, especially after the twelve-week CR programme. Interviewees felt left alone without further support and described feelings of being entitled to more support than what was

available to them. Contrastingly, several reports from The Danish Heart Association have found Danish Heart Patients in general to describe satisfaction with the available services, albeit worries about the time after the twelve weeks programme is a general finding (154–157). According to the Tanahashi framework, the availability domain covers aspects of the resources available, including health services and health professionals. Registrations in the Danish Cardiac Rehabilitation Database have indicated that availability of CR is an issue that needs to be addressed (158). With more people surviving IHD, there is also an increasing body of research on CR, preventive medications and other measures in secondary prevention of IHD (159). However, shifts in scientific foci are not necessarily followed by clinical practice; and the large EUROASPIRE surveys on contributing life style factors of patients with CVD from Czech Republic, Finland, France, Germany, Hungary, Italy, the Netherlands, and Slovenia found that healthcare systems were continuously dominated by acute care, medical technology, devices, and pharmacological treatments (159). Moreover, the Danish healthcare system experiences increasing problems with low density of health facilities and skilled health workers in more remote and/or deprived areas of Denmark. Together with social inequalities in health status, with more multimorbidity and unfavourable sociodemographic determinants among socially marginalized groups, these factors contribute to social inequalities in the availability domain (160,161). Specific for the migrant population is also the question of legal entitlements to health, where preventive healthcare in Denmark, as in many other countries, is not available for the subpopulation of undocumented migrants (162,163).

#### **Accessibility – Substudies I, III & IV**

**Substudy I** found that the lower use of preventive medications and patient education among migrants compared to Danish-born, was not eliminated when adjusting for comorbidity or sociodemographic factors, and these factors therefore did not explain the observed differences in realised access. Nevertheless, sociodemographic factors and comorbidity may be barriers to use of CR in the general population, as well as among migrants. Below follows a short discussion of the identified barriers to accessibility to CR for migrants.

**Financial barriers:** In **substudy I**, the largest between-group differences were found in medication persistence, for which there is user payment. This was also found in a previous Danish study, where under-use of healthcare among non-Western migrants was only present for services with user payment, despite adjustment for sociodemographic factors (126). The presence of financial barriers to CR was supported by findings from **substudy IV**, where poor

family finances were described as barriers to use of preventive medications and to sustainment of physical exercise after the twelve-week exercise programme had been completed. Previous studies have likewise found poor finances to be a predictor for use of CR in general (76,164), and among ethnic minority groups (165).

**Distance to the provider:** In *Substudy IV*, interviewees experienced distance to CR services as a barrier to access. This is a well-known barrier to CR in general populations (77,80,87,166,167) and has been addressed in experimental studies aiming to minimize or eliminate it, e.g. by testing home-based exercise programmes. A Danish study found equal effects of home-based versus centre-based exercise (168); and a study from the UK had similar findings in a cohort with a high proportion of ethnic minorities (169). However, home-based CR has been evaluated as less cost-effective and introduces new barriers such as lack of motivation, and missing the benefits of social interaction (169,170).

**Comorbidity:** In *substudy IV* Interviewees endorsed musculoskeletal comorbidities specifically as barriers; and this is also known from general populations (77,170,171). Findings of substudy IV revealed how musculoskeletal diseases and IHD formed a vicious downwards circle of immobility, pain, anxiety and social isolation, and overcoming the access barriers to CR may be the key to turning this downward movement. For instance, an observational study found significant higher quality of life and survival among CVD patients with musculoskeletal comorbidities who had participated in CR, compared to non-participants (172).

**Language:** *Substudy III* addressed language barriers at the system-level. Of the included municipalities, 84 % (n=26/31) offered interpretation services and only one (3% (n=1/31) provided multilingual information material. There appeared to be fewer language barriers at hospitals, with 100 % (n=19/19) providing interpreter services and 32% (n=6/19) providing multilingual information material. The differences in provision of interpretation may relate to differences in legislation. Hospital-based activities refer to the Danish Health Law (134), which gives clearer directions on patients' right to interpreter than the Public Administration Law (173), which municipalities operate under. However, a new bill will prevent migrants with three or more years of residency in Denmark from receiving interpreter services free of charge (174). If enacted, this bill is likely to affect a large number of migrants, add extra administrative burdens to health professionals' daily tasks, increase errors, decrease use of planned healthcare visits and increase use of acute healthcare (175,176). Finally, limiting access to interpretation is not cost-effective; e.g. a recent study, including 8077 discharges from medical care units, tested

a convenient interpretation access in form of a dual-handset interpreter telephone and found significant effect in the form of reduced rehospitalizations, equivalent to an estimated monthly hospital expenditure savings of \$161 404 (177).

In **Substudy IV** language barriers were identified in inter-sectorial transitions from hospitals to municipality-based CR in the form of e.g. referral letters written in Danish only. Therefore, some had to rely on the help of relatives who were more fluent in Danish. Interpretation was not only of language, but also of migrant patients' representations of IHD-symptoms. Experienced need for help from relatives to interpret and navigate through the system is also found in previous qualitative studies including South-Asian ethnic minorities with recent IHD (178,179).

**Gender:** In recruitment of interviewees to **substudy IV**, clear indications on gender-related barriers occurred. Even though interviews were rich, and saturation was reached for most topics, only one woman was included, and I was not able to elaborate much on the role of gender. However, gender might be of fundamental importance, e.g. with respect to how illness affects changes of the perceived self; and apparently gender also played a role in access to CR. As described in the *material and methods*-section, only four out of the 31 (13%) identified interview candidates were women. Relatively to this stands inventories from the Danish Cardiac Rehabilitation Database, where approximately thirty percent of patients who initiated CR in the capital Region in 2016 were women (180). Hence, specifically for the migrant population, there seems to be substantial gender-related barriers to CR. Previous studies on women's' participation in CR have found that women were less likely than men to be referred to, and participate in, CR (77,181–184), and ethnic minority women were less likely to be referred to CR, compared to men and ethnic majority women (165,185,186). Referral by physician is a known predictor for CR participation, and a Canadian study assessed physicians' tacit and stated judgment policies in referral decisions. The study found wide variation among physicians, and self-insight was modest, with evidence of systematic gender bias as they judged women as less likely than men to benefit from CR (187). It is justifiable to hypothesize that differences in referral of migrant women may have some connection to language-proficiency. This rests on the fact that non-Western migrant women in Denmark are less likely to be employed (15) and the hypothesis that employment is linked to improved language proficiency in the local language. Correspondingly, a review found limited English-language proficiency to be a predictor for non-referral (188); and other studies have found differences in referral according to ethnic minority status (184,189,190). More systematized strategies for referral have showed to counter these



observed inequalities (191,192). A questionnaire study also found that some women needed their husbands' approval to participate in CR (193). Lastly, apart from being disadvantaged in realised access to CR, a study assessing recovering after IHD have found ethnic minority women to be further disadvantaged in relation to physical recovery (194), and a study from the US found lower mortality among CR-initiators compared to non-initiators, in a population of ethnic minority patients (195).

#### **Acceptability – Substudy IV**

*Substudy IV* addressed acceptability of CR and preventive medications. Apart from the financial expenses, preventive medications were described as acceptable by most interviewees.

Acceptability of physical exercise, dietary advice and patient education was bound up to the social and cultural contexts of interviewees in the sense that life-style changes that did not fit with interviewees taste, norms and routines were less likely to be implemented and maintained. Norms, taste and routines are important demarcations of social and cultural identity; and consequently, life-style changes may be perceived as threats to social identity if they fail to take the social and cultural context into consideration (196).

Another related finding was the need for social belonging as a motivator for behaviour (143). Interviewees described how maintaining a sense of social belonging was likely to be prioritized above the prevention of a potential future health threat; and the implementation and sustainment of life-style interventions were therefore linked to the concept of sense of belonging. Previous studies have found that establishing a sense of belonging to family and community is essential for wellbeing among different migrant populations (144,145). The need to take the social and cultural context of ethnic minorities into consideration in the planning of life-style interventions has also been found in studies from the UK on South-Asian minorities in CR (178,186,197). In an attempt to address this finding, a tailored CR intervention for women of South-Asian minority background have been tested showing promising results in engaging the women in activities that they endorsed as 'appropriate' e.g. dance group exclusively for women (90).

#### **Contact coverage – Substudy I**

*Substudy I* addressed the contact coverage domain by comparing use of preventive medications, physical exercise, dietary advice and patient education among Western and non-Western migrants with Danish-born as reference. Non-Western migrants were found to have lower initiation of ADP- and ACE-inhibitors and higher risks of discontinuation of all medications

included in the study. These findings are supported by previous studies (94–96,198–200). For non-pharmacological interventions, lower initiation of patient education and fewer contacts for physical exercise and patient education were found in non-Western migrants. Previous studies have applied differential methods to assess use of non-pharmacological CR-interventions in migrant populations, but they are hampered by low registration of data among minority groups (201), or with risks of selection bias (85,202).

Findings call for concrete actions to address the barriers to realised access that causes inequalities in use. Reviews on interventions to improve adherence to medications and non-pharmacological interventions find that telephonic reminders, feed-back to the patients and mutual agreements may be effective (203,204), but a systematic Cochrane review found no evidence for any adherence promoting interventions in use of CR in general populations (83). Much hope and resources are put into the development eHealth technologies in the prevention of chronic disease, but evidence is still lacking for the effectiveness in secondary prevention of IHD (205). Specific studies on migrant populations and effective adherence-enhancing interventions have hitherto been too few and heterogeneous to conclude on (206), but within other research fields, such as maternal health, eHealth technologies are promising and may lead the way forward to overcome migrant-specific barriers (207).

### **Effectiveness – Substudy II**

*Substudy II* addressed effective access to CR by evaluating associations between patient education and subsequent medication persistence. The study did not give any firm answers to causal inferences and should be supplemented by studies with experimental designs. Nevertheless, the substudy offered insight into effectiveness in an unselected population; and by stratification of the study population according to migrant background, it gave specific insight into effectiveness of patient education in the Western and non-Western migrant populations. Stratification according to migrant background showed a heterogeneous pattern with significantly stronger effect in migrants for initiation of ADP-inhibitors, weaker effect for initiation of statins among migrants with only 1-2 contacts for patient education, and no significant effect modifications by migrant background for discontinuation of medications. The findings support an increased attention towards including more migrants in life-style interventions, but also showed that education in phase II CR is more effective for initiation than for long-term medication persistence. A systematic review has assessed effect of patient education on cardiac patients' knowledge, psychosocial indicators or behavioural changes of

smoking, physical activity, dietary habits, response to cardiac symptoms, and medication adherence (208). The included studies were criticized for not being sufficiently thorough in their description of the interventions, but the educational interventions showed improvements in patients' knowledge, physical activity, dietary habits and smoking cessation. A systematic Cochrane review, focusing on hard end-points, was not able to identify effect of patient education on mortality, but some evidence suggested effect on morbidity and quality of life. Again, the included studies were heterogeneous in their description of the intervention; and the review calls for more studies on the effect of patient education in ethnic minority populations (7). Lastly, a Danish RCT has found patient education to be effective in improving IHD patients' adherence to physical exercise (209).

Another Danish study have tested the effects of a tailored programme for socially vulnerable patients, defined as patients who were unemployed and/or living alone. The study found effects on use of CR and on blood pressure, weight, lipid status and medication adherence (84,89). For female patients, a study has found different effects of a tailored educational programme among local-born and ethnic minorities with IHD, suggesting that there is a need for CR programmes to be particularly attentive to the needs and benefits of CR among migrants (210).

## **Reviewing effective access to healthcare**

The Tanahashi framework has been described as a useful tool to identify possible bottlenecks in different population groups' access to healthcare, and to facilitate the transmission of research findings into practice guidelines (9,106). As an example, WHO's recent publication for reviewing inequalities in national health programmes, the INNOV8 framework, includes the Tanahashi framework as one of eight steps towards inclusive healthcare programmes (9). The INNOV8 framework is rooted in the principles of the right to health (13), universal health coverage (11), and the Universal Sustainable Development Goals (SDGs) (211). The two overall goals of the INNOV8 framework are 1) to understand why some populations are being left behind and factors contributing to this; and 2) to explore how to respond to these challenges concretely and effectively. As described, the goals are closely related to the aims and research questions of this thesis. However, aims of the thesis mainly relate to the first goal; and the second goal is the next step; using the findings from this thesis to respond concretely and effectively to the identified inequalities.

# Conclusions and perspectives

## Conclusions

The substudies gave different perspectives on migrants' realised and effective access to CR, experiences with being a migrant in CR and in the intersection between different parts of the healthcare system.

Inequalities in realized access to CR and use of preventive medications were identified; and socio-demography and comorbidity could not explain the lower use among migrants. Barriers to access were identified at both patient and provider levels and were related to poor family finances, distance to provider, comorbidity, language and gender. Barriers to access were also ascribed to the acceptability domain of the Tanahashi framework; and findings showed migrants' difficulties with the implementation and sustainment of life-style changes if the changes were in conflict with the norms and routines of migrants' social and cultural contexts. Relatives who supported with interpretation and with navigating in the healthcare system enabled access to CR. Lastly, the findings supported patient education as a component of CR for improving medication persistence among migrant- as well as local-born patients with recent IHD, thus indicating that the bottlenecks in effective access to CR for the migrant population are related to barriers in accessibility and acceptability, rather than effectiveness.

## Implications for policy and practice

Given the established evidence on effectiveness of CR on quality of life, morbidity and mortality, there is reason to believe that the identified inequalities have implications for well-being and longevity among migrant populations. Low use of CR and preventive medications is a problem in general IHD-populations; and interventions to improve use of CR and preventive medications could be aimed at the general IHD-population. However, the thesis identified specific barriers for migrants, and these findings stand in favour of more targeted interventions. Modifiable barriers at the system-level should be addressed by ensuring availability of CR services, ensuring that access to CR and medications stays at low costs or free of charge; and by providing interpreter services and multilingual information material. Albeit language barriers are unlikely to be eradicated; it must be acknowledged that preventing patients from accessing care by limiting access to interpretation, equals putting some of the most vulnerable patients at poorer

odds. The reduction of this gap in access is much needed, but at times counteracted at the political level despite evidence for cost-effectiveness of easy at-hand interpretation.

Modifiable barriers at the provider-level should be addressed by raising awareness among health professionals about diversity sensitiveness and the importance of taking the social and cultural contexts of the patients into consideration, which would be for the benefit of all patients.

Modifiable barriers at the patient level should be addressed by improving equal and effective access to CR, which would strengthen patients' self-management of IHD. Moreover, development, implementation and monitoring of effective and inclusive interventions require the availability of data of good quality. It is thus in the interest of society to support ongoing data assembly of high-quality that includes information on vulnerable populations.

Another implication of this thesis relates to the question of how knowledge on former migration policies can inform future policies. Substudies I and IV zoomed in on subpopulations that mainly immigrated to Denmark as low-skilled labour migrants during times with absent or very limited reception programmes for newly arrived migrants. The combination of short educations, limited Danish language-proficiency, poor family finances and physical strenuous jobs was found to form a vicious downward circle of poor health, immobility, financial problems and difficulties with accessing healthcare. Most interviewees in substudy IV had been in occupation, which is often referred to in the public as the key to integration. However, substudy IV indicated that occupation cannot stand alone, but must be accompanied by other interventions, such as language courses and other forms of education. Furthermore, in times of illness and dependability the downside effects of segregation stand clearer; and being part of society and enjoying the support of relatives is important for the health and well-being of migrants, as well as non-migrants.

### **Implications for research**

The thesis identified several areas in need for further research. Gender differences in migrants' access to CR were not in the focus of the thesis and needs more scientific focus at the system-, provider- and patient levels. The thesis was explanatory and explorative in its approach and findings must be transferred to interventions for improving accessibility, acceptability and effectiveness of CR at the patient-, provider-, and system-levels.

At the patient level, interventions could use computer-assisted technology, e.g. applications designed to overcome language barriers or designed to engage patients in disease management by self-monitoring and feed-back to the patient. The appliance of new technologies may also meet requirements for cost-effectiveness, albeit this is not to be taken for given; and cost-effectiveness must continuously be measured with the inclusion of indicators for e.g. rehospitalizations and expenditures for sick-leave. The design of interventions for improving access can also be informed by identified enabling factors. Social support and social belongingness were identified as important factors; and previously developed interventions including peers from same ethnic groups have shown promising prospects, and may be implemented across different specialties, but needs further testing. Other approaches, which consider the social context, may be to engage the family more in the patient trajectory, e.g. by a systemic approach, and hereby focusing on the role of the family as a caring unit. The systemic approach has also proven useful in addressing the resources of the individual and the family. At the provider-level, the need for more diversity sensitiveness must be addressed by rigorous experimental studies on the effect of pre- and postgraduate educational programmes. Furthermore, the transition from phase II to phase III in CR needs more attention, and if the primary care sector and general practitioners are to play a central role in sustainment of life-style changes and medication adherence, they need both education and time to undertake this task. At the system level, inclusive healthcare systems must be secured by allocating sufficient resources, and by working for a holistic system that encompasses the complexity of the individual patients, including those with multimorbidity, migrants and other potentially marginalized groups. We must therefore continue to monitor and explore marginalized groups' realised and effective access to healthcare. Some may not have a strong voice in the public, and identification and dissemination of inequalities are prerequisites to securing more inclusive healthcare systems. Importantly, migrant and ethnic minority research must continuously consider heterogeneity of the migrant population and avoid exaggerations of differences between local-born and migrants, which may direct focus away from inequalities that should be ascribed to social and economic factors.

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## Appendices

- I. Frederiksen HW, Zwisler AD, Johnsen SP, Öztürk B, Lindhardt T, Norredam M. Differences in initiation and discontinuation of preventive medications and use of non-pharmacological interventions after acute coronary syndrome among migrants and Danish-born. *European Heart Journal*. Accepted for publication. March 2018.
- II. Frederiksen HW, Zwisler AD, Johnsen SP, Öztürk B, Lindhardt T, Norredam M. Education of migrant and non-migrant patients is associated with initiation and discontinuation of preventive medications for acute coronary syndrome. *Submitted*.
- III. Al-Sharifi F, Frederiksen HW, Rossau HK, Norredam M, Zwisler AD. Access to cardiac rehabilitation and the role of language barriers in the provision of cardiac rehabilitation to migrants. *Submitted*.
- IV. Frederiksen HW Norredam M, Zwisler AD, Lindhardt T. Rehabilitation and everyday life among migrants with ischemic heart disease. *Submitted*.

Ovenstående artikler er ikke vist i denne pdf-udgave. Kontakt Hanne Winther Frederiksen for yderligere information.



# DECLARATION OF CO-AUTHORSHIP

Information on PhD student:	
Name of PhD student	Hanne Winther Frederiksen
E-mail	hanne.winther.frederiksen@regionh.dk
Date of birth	23. February 1978
Work place	Herlev Hospital
Principal supervisor	Marie Norredam

Title of PhD thesis:
Cardiac Rehabilitation among migrants



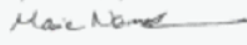
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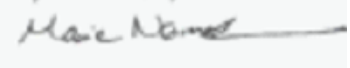
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2. Planning of the experiments and methodology design, including selection of methods and method development	C
3. Involvement in the experimental work	B
4. Presentation, interpretation and discussion in a journal article format of obtained data	C

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Signature of the co-authors:			
Date:	Name:	Title:	Signature:
27.02.2018	Hanne Winther Frederiksen	PhD student	
05.03.2018	Ann-Dorthe Zwisler	Professor	
06.03.2018	Søren Paaske Johnsen	Associate Professor	



06.03.2018	Buket Öztürk	Statistician	
06.03.2018	Tove Lindhardt	Senior Researcher	
06.03.2018	Marie Norredam	Associate Professor	

Signature of the PhD student and the principal supervisor:			
Date: 27.02.2018		Date: 06.03.2018	
PhD student: 		Principal supervisor: 	



# DECLARATION OF CO-AUTHORSHIP

Information on PhD student:	
Name of PhD student	Hanne Winther Frederiksen
E-mail	hanne.winther.frederiksen@regionh.dk
Date of birth	23. February 1978
Work place	Herlev Hospital
Principal supervisor	Marie Norredam



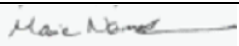
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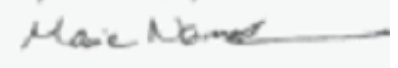
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06.03.2018	Søren Paaske Johnsen	Associate Professor	

06.03.2018	Buket Öztürk	Statistician	
06.03.2018	Tove Lindhardt	Senior Researcher	
06.03.2018	Marie Norredam	Associate Professor	

Signature of the PhD student and the principal supervisor:			
Date: 06.03.2018		Date: 06.03.2018	
PhD student:		Principal supervisor:	



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Name of PhD student	Hanne Winther Frederiksen
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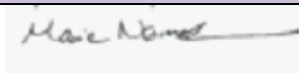
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Signature of the co-authors:			
Date:	Name:	Title:	Signature:
06.03.2018	Fatima Al-Sharifi	Medical Student	
27.02.2018	Hanne Winther Frederiksen	PhD student	
06.03.2018	Henriette Knold Rossau	Research Assistant	

06.03.2018	Marie Norredam	Associate Professor	
05.03.2018	Ann-Dorthe Zwisler	Professor	

Signature of the PhD student and the principal supervisor:			
Date: 06.03.2018		Date: 06.03.2018	
			
PhD student:		Principal supervisor:	



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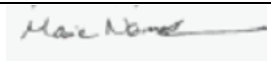

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05.03.2018	Ann-Dorthe Zwisler	Professor	

06.03.2018	Tove Lindhardt	Senior Researcher	

Signature of the PhD student and the principal supervisor:			
Date: 06.03.2018		Date: 06.03.2018	
			
PhD student:		Principal supervisor.	