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The publics' perspective on cardiovascular risk information

Implications for practice

ÅSA GRAUMAN

Dissertation presented at Uppsala University to be publicly examined in Sal IX, Universitetshuset, Biskopsgatan 3, Uppsala, Friday, 19 February 2021 at 09:15 for the degree of Doctor of Philosophy (Faculty of Medicine). The examination will be conducted in English. Faculty examiner: Doctor Liesbeth Claassen (National Institute for Public Health and the Environment, The Netherlands).

Abstract
Grauman, Å. 2021. The publics' perspective on cardiovascular risk information. Implications for practice. *Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine* 1710. 79 pp. Uppsala: Acta Universitatis Upsaliensis. ISBN 978-91-513-1096-1.

Lay people struggle to understand the implications of cardiovascular risk information. With new advanced testing techniques and the digitalization of personal health information, the communication of cardiovascular risk becomes a challenge.

The overall aim of the thesis was to investigate the publics' perspective of cardiovascular risk information through a multi-method approach, including how individuals perceive risk, factors affecting an underestimation of risk, how cardiovascular risk communication affects individuals' psychosocial health, and their preferences for risk communication.

In study I, research participants' perceptions about risk information were explored in five focus group interviews. The participants' (n=31) perceptions about cardiovascular risk were complex, where multifactorial aspects were disregarded. The communication of cardiovascular risk information did not meet the participants' need for understanding, support, and guidance regarding what to do with this information.

Study II was a before-after investigation regarding the impact of cardiovascular risk information on research participants' health-related quality of life and mental distress. Increased worry and anxiety were observed in individuals referred to hospital because of coronary artery stenosis.

Study III was a cross-sectional study, which found that individuals with a very good or excellent self-perceived general health and individuals without a family history of CVD were more likely to underestimate their cardiovascular risk compared to participants with poor or fairly good general health and without a family history.

Study IV was a cross-sectional study, investigating the preferences of the Swedish population for communication of cardiovascular risk information from a health checkup using a Discrete Choice Experiment. Besides cost, consultation time was the most important aspect when communicating cardiovascular risk.

The findings suggest that cardiovascular risk communication does not reach its fullest potential when it comes to recipients' perspective of the benefits of CV risk communication. Improvements should aim at increasing the recipients' personal control and health literacy and furthermore, acknowledge the fact that self-perceived risk is influenced by how a person feels in general and experiences of family history.

Keywords: Cardiovascular diseases, Health checks, Risk communication, Cardiovascular risk communication, Optimistic bias, Family history, General health, Preferences, Public perspective, Prevention, Mental distress, Health related quality of life

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To Anton and Ines,

The cure for boredom is curiosity.
There is no cure for curiosity.
(Dorothy Parker)

List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

I   Grauman, Å., Hansson, M., James, S., Höglund, A. (2019) Exploring research participants' perceptions of cardiovascular risk information-Room for improvement and empowerment. *Patient Education and Counselling,* 102: 1528-1534.

II   Grauman, Å., Hansson, MG, Puranen A, James, S., Veldwijk, J (2019). Short-term mental distress in research participants after receiving cardiovascular risk information. *PloS One,* 14: e0217247.

III   Grauman, Å., Veldwijk, J., Hansson, M., James, S., Byberg, L. (2020). Good general health and lack of family history influence the underestimation of cardiovascular risk: A cross sectional study. (*In Manuscript*)

IV   Grauman, Å., Hansson, M., James, S., Hauber, B., Veldwijk, J. (2020). Communicating test results from a general health checkup: the public's preferences from a discrete choice experiment survey. *(In Manuscript)*

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Contents

Abbreviations

BMI	Body Mass Index
CVD	Cardiovascular Disease
CV	Cardiovascular
CI	Confidence Interval
CT	Computed Tomography
DCE	Discrete Choice Experiment
FDA	Federal Food and Drug Administration
GCOS-24	The Genetic Counseling Outcome Scale
HADS	Hospital Anxiety and Depression Scale
HRQL	Health-Related Quality of Life
HL	Health Literacy
HTA	Health Technology Assessment
MI	Myocardial Infarction
MCS	Mental Component Score
MRI	Magnetic Resonance Imaging
NGT	Nominal Group Technique
OR	Odds Ratio
RERI	Relative Excess Risk due to Interaction
PCS	Physical Component Score
PHCC	Primary Health Care Center
PRO	Patient Reported Outcome
PPI	Patient Preference Information
SCORE	Systematic Coronary Risk Estimation
SCAPIS	The Swedish CardioPulmonary BioImage Study
SDM	Shared Decision-Making
SF-12	Short Form Health Survey 12
WHO	World Health Organization
YLL	Years of Life Lost

Introduction

To prevent cardiovascular diseases (CVDs), primary health care centers can invite asymptomatic individuals to general health checkups. These health checkups can provide an opportunity to promote and reinforce healthy lifestyle behaviors and to identify high-risk individuals that would benefit from drug treatment. Individuals can also choose to undergo health checkups provided on the free market, offered to anyone who can afford them. There are various health checkup options, from very basic to "full body scans" that can cost up to 50,000 SEK, where magnetic resonance imaging (MRI), and an ultrasound examination of the heart are included. The availability of health tests may reflect the strong focus on health in today's society and is facilitated by technological innovations that provide new and advanced testing, enabling earlier detection of abnormalities in asymptomatic individuals. Such tests including high-resolution ultrasound, (MRI) and computed tomography (CT) angiography, among others, were used in the Swedish CardioPulmonaryBioImageStudy (SCAPIS), with the purpose of examining the carotid and coronary arteries of 30,000 men and women. SCAPIS is a population-based cohort for the study of cardiovascular disease (CVD) and chronic obstructive pulmonary disease (COPD), which aims to enable advanced risk profiling and personalized medicine [1].

A parallel development in information technology and digitalization of health data provides the public with increased access to personal health information, thus, allowing them to monitor their health. Examples include electronic medical health records provided by health care services, but also health data collected by the individual him or herself through e.g., health-apps and watches.

It is expected that the increased access to health information will empower individuals and in the long-run lead to better health [2]. However, lay people often experience difficulties in understanding the implications of risk information. It may also cause worry and affect quality of life about something that may, but not necessarily will, happen since risk involves uncertainty regarding to whom, if, and when disease will occur. Therefore, this trend will lead to challenges when it comes to presenting and communicating personal risk information. These challenges can only be solved by listening to those affected by the risk communication and assessing their perceptions, experiences and preferences. Their perspective will be the focus of this thesis.

Background

Preventing cardiovascular diseases

Cardiovascular risk factors

To promote and protect the health of the public, it is essential to know which conditions contribute most to the burden of disease in a population and what causes and determines health and illness. Cardiovascular diseases (CVD) have been the number one cause of death and are the main cause of years of life lost (YLL) during the last twenty years, both in Sweden and globally [3, 4]. Men and women have the same lifetime risk of experiencing CVD, but the mean age for having the first acute myocardial infarction is nine years younger for men compared to women [5]. The multifactorial etiology of CVDs and other lifestyle related chronic diseases makes it difficult to pinpoint a single cause. Nonetheless, there are protective factors that can decrease the negative effects of the risk factors. CVDs, in general, are the result of multiple, interacting risk factors [6]. The majority of the factors affecting CVD are modifiable. While smoking, a sedentary lifestyle, hypertension, diabetes, high cholesterol level, obesity, and negative psychosocial factors such as stress and depression are risk factors for CVD, daily consumption fruits and vegetables and exercise are protective factors.

The health of an individual and a population has multi-dimensional causes and is determined by factors associated with the individual, the community, living conditions, and the environment as well as to governmental policies and laws. Health has its roots before a child is even born, and the risk of ill health can accumulate across life stages and generations [7]. Lifestyle behavior is socially conditioned and related to psychosocial factors (e.g., stress and depression) and socioeconomic and demographic factors (e.g., age, education, social status, ethnicity, profession, and living condition), which indirectly affect one's CVD risk. Vulnerable groups who are economically constrained and less educated more often have several risk factors accumulated, and absence of protective factors [6]. This is reflected in the mortality rate for CVD, which is not equal for everyone in the population, but differs a lot due to demographic and socioeconomic factors. For women with only primary education, the mortality rate is doubled compared to women with post-secondary education. In fact, CVD is the major cause of differences in the population's

health in the northern European countries [8-10]. This is to a great extent dependent on socioeconomic differences in modifiable risk factors [11].

Prevention strategies

The World Health Organization (WHO) views health as a personal resource in everyday life, needed for social, economic, and personal development. The WHO defines health as "a state of complete physical, mental and social well-being and not only the absence of illness." Furthermore, health is an important dimension of quality of life and a fundamental human right. Likewise, the health of the population is seen as a resource for the development and prosperity of the society, hence a public concern. Therefore, health is highly valued in today's society, and promotion and protection of health through preventive interventions are prioritized [12]. This holistic definition stands in contrast to the more narrow biomedical definition of health, where health is assessed objectively through diagnostic testing by health clinicians. Instead, the WHO's definition of health requires that the individual assesses some dimensions of health, based on his or her subjective experience [13].

Often prevention interventions does not prevent illness from occurring; rather, illness is postponed, so we can live healthier and longer. To affect the populations' health, there is usually a need to work in parallel at different levels in society. Since many illnesses share the same risk factors (CVDs, diabetes, and some cancers), one intervention can prevent several conditions.

There are different strategies to promote and protect the health of a population. Primary prevention aims to prevent disease or injury from occurring and therefore focus on healthy individuals. Secondary prevention aims to detect and treat a disease at an early stage to improve chances of being cured or negative consequences of the condition. Secondary prevention is focused on individuals, where the disease has already developed and aims to prevent relapses or impairment from the disease, e.g., cessation of smoking or preventive drug treatment after a myocardial infarction to prevent further events from occurring. Other examples are screening of asymptomatic individuals for specific disease to detect it at an early stage and thereby improving the chances of successful treatment (e.g., cancer screening) or to screen the population for risk factors (e.g., high blood pressure, lifestyle factors). Health promotion focuses on positive health enhancement and aims to increase the protective factors that make the population healthy and resistant, mainly through the improvement of social conditions [13].

Prevention can entail low-risk and high-risk strategies [6]. Low-risk strategies include population-based interventions that bring enormous benefits to the community but offer little to each individual, since they might never have developed the disease (The prevention paradox). In population-based interventions, many people must take preventive action in order to prevent illness (or injury) in only a few, since no one can say who will be a future case. Minor

changes made by the population can have a big impact on the overall mortality, since a large number of people exposed to a small risk can generate many more cases than a small number exposed to a high risk [14]. Population-based interventions to prevent CVD include banning smoking in public areas, urban planning to increase daily physical activity, taxes on unhealthy foods, and nudging to make healthy choices the default e.g., by removing candy from the checkout counter. At an even higher structural level, CVD prevention can include improving structural life conditions such as education and working conditions [15]. High-risk strategies focus on identifying high-risk individuals who are most likely to develop the disease, including specific sub-groups.

Cardiovascular risk assessment

Health care professionals have a unique opportunity to apply individualized prevention strategies in their everyday work. By performing CVD risk assessment in asymptomatic individuals, high-risk individuals can be identified. The European Guidelines on Cardiovascular Disease Prevention in Clinical Practice recommends systematic assessment of the cardiovascular risk in asymptomatic men > 40 years old and women >50 years old. The risk assessment should be done using Systematic Coronary Risk Estimation (SCORE). It estimates the ten-year risk of a first atherosclerotic fatal event and helps to identify individuals who are most likely to benefit from drug therapy. SCORE builds on age, sex, smoking, systolic blood pressure, and total cholesterol level [16]. A family history of premature CVD is also relevant when assessing the cardiovascular risk of an individual, as it reflects both on genetic traits and the living conditions such as lifestyle and environmental factors shared within a family [16].

Risk assessment should be a combination of both opportunistic and systematic screening and be repeated, e.g., every five years. Systematic CVD screening can be performed through general health checkups where a selected part of the population is invited to be tested for cardiovascular risk factors. Studies have found that health checkups can have a positive impact on CVD risk factors [17, 18], the mortality in high risk individuals [19], and all-cause and CVD mortality [20]. However, attendance rates (particularly in those who are at the highest risk) and adherence are identified issues that need to be improved to optimize the utility of such health checkups [16], since the effectiveness of health checkups depends on participation rates.

In Sweden, the 21 autonomous Regions have the responsibility for health care and decide on whether to offer subsidized general health checkups for their population. Among the regions that offer these, the design and the out-of-pocket costs for the health checkups differ. General health checkups include some level of testing (e.g., blood pressure and glucose) and is often followed-up by a health counseling session with a trained nurse that focuses on lifestyle changes. The out-of-pocket cost for the citizens varies between 200–

300 SEK (free-of-charge in some regions). In addition to general health checkups, there are various private options available where the price is considerably higher. Many employers also offer health checkups for their employees through occupational health care services. For some rare cardiogenetic diseases, such as familial hypercholesterolemia (FH), cascade screening is the recommended strategy to detect and diagnose family members at an early stage [21]. FH is the most common hereditary heart disease in Sweden but is currently underdiagnosed. It is associated with an increased risk of heart attack or stroke at a young age (before 50 for men and before 60 for women) [22].

Defining and predicting risk

Risk is an essential concept in preventive medicine and in daily clinical care, and its different meanings will affect the assessment of risk, prediction, communication, and understanding of personal risk. Different disciplines and theories define risk differently. From a medical perspective, risk is defined as probabilities calculated through scientific facts, as a function of a) the likelihood and b) the value of a possible event [23]. The likelihood is the calculated probability and can thus be seen as something rather objective and neutral. However, there is always a subjective dimension of value and norms when we measure and communicate a risk [24]. Individual perspectives and experiences as well as the values and norms in a society influence what is perceived as a negative event and often vary between experts, patients, relatives, regulators, and among individuals [25].

Risk prediction is the fundament in all prevention. By looking at the past and present we are trying to predict the future, to be able to take responsibility for the future health by interfering somewhere in the causal chain. Health risk is estimated by experts based on epidemiological data of the mean distribution of risk factors and disease in a population. The evidence comes from observational epidemiological studies where statistical associations are the main findings, which create uncertainty around the causal chain. The very nature of risk means that there is a need to acknowledge and act under a level of uncertainty in order to manage and take control over it [23]. The uncertainty involved in risk prediction makes it problematic to assess the precise risk of an individual and difficult to know exactly who will become ill, as well as who exactly will benefit from a treatment or preventive measure.

The risk of developing a disease and the responsiveness to a drug or lifestyle change is partly affected by individuals' traits and circumstances of life, including genotype, biomarkers, lifestyle, and environment and can vary between individuals. Personalized medicine uses a combination of such information about individual differences to optimize prevention, diagnosis, and treatment by predicting individual disease risk and treatment response. Advanced risk profiling will enable the prediction of manifestation of disease and facilitate early treatment for those individuals who are at increased risk but yet

without a clinically manifested illness. With the emergence of new technologies, including sequencing of the human genome, medical diagnostics, and single nucleotide polymorphism (SNP) genotyping, personalized medicine is gradually being realized [26, 27]. The progress in identifying genes responsible for cardiovascular diseases can only be considered modest compared to other disease areas. Instead, there is more progress in the technological development regarding testing of biomarkers as well as plaque composition and stability [26].

Early detection of disease and risk factors can be beneficial if it improves prognosis, leading to improvements in quality of life or extended life years, or if it enables milder treatment options [28]. However, the increased possibilities of early detection also come with concerns about increased overdiagnosis and overtreatment [29, 30]. Overdiagnosis means the diagnosis of individuals with a condition that would never have caused symptoms or shortened the patient's lifetime if left undetected. Low-risk individuals are thereby labeled with a medical condition or "at risk," which can cause them to worry and influence their self-perceived health. They might also be treated for the rest of their life with a treatment that will not benefit them and, even worse, only cause side-effects [29].

Overdiagnosis is caused, among many things, by inappropriate use of diagnosis criteria and confusion between risk and disease, which changes the cut-off between healthy and ill [30, 31]. The technological innovations might therefore also influence how disease is defined and who will be identified as "healthy," "at-risk," or "sick" [29]. The cut-offs for diagnosis and treatment are dichotomous decisions decided by the medical society [29]. However, risk and disease are rather continuous concepts, which makes decisional thresholds to diagnose or to trigger interventions problematic and more arbitrary than what might be communicated to patients [6, 16, 29]. However, it is not always possible to know beforehand which patients are over-treated and which patients have a genuine need [29]. Hopefully, individualized risk prediction models can help to avoid overdiagnosis.

Communicating and (mis-)understanding risk

With health checkups comes the challenge of communicating test results and thereby the individual's CVD risk. Effective risk management depends on the trust that the recipients have in the sender. To earn and maintain trust, authorities and experts hold an ethical responsibility to be transparent about what they know about risks and share information with those whom it may concern. Otherwise, the public might feel they have been denied information that is vital to make an informed decision about their health [32].

People generally want information about their personal health. However, individuals often think the information provided by the health care is difficult

to understand [33]. Moreover, they often want to have more information than what is offered [34].

The goals with communicating personal information about health and risk may vary. It can be to affect knowledge, attitudes, or beliefs; or to change behavior and stimulate protective measures [32, 35]. It has been found that cardiovascular risk information encourages patients intention to take action to reduce their risk, especially in high-risk patients [36]. However, many CVD risk communication interventions have failed to improve the actual lifestyle behavior, blood pressure, or blood lipids of their target population [37].

Risk communication is complex and misunderstandings are easy. We humans have a limited capacity to process information. In everyday life, we are exposed to a massive amount of information. People are more susceptible to risk messages when they are looking for information themselves and at times when they feel vulnerable. The timing of risk communication, therefore, is essential [32]. How risks are presented plays a crucial role in how individuals will perceive the risks, their emotional response to the risks, their intention to change their behavior, and their decisions about accepting medical treatment [36].

Information is interpreted based on a person's pre-existing beliefs and values that have been acquired over a lifetime, i.e., their "mental model" of the topic. These beliefs will influence how messages are interpreted and instructions followed. People tend to look for and accept messages that are consistent with their pre-existing understanding. New and deviating facts may be viewed with suspicion, and risk being rejected if they deviate too much from people's existing beliefs [38]. Therefore, it is crucial to have knowledge about the responders' perception of CVD risk in order to design optimal risk information.

People do not share the same pre-understanding and view of the world. Experts and lay people usually think differently about risks, which is a challenging factor when communicating risks. Experts often to build risk communication on scientific evidence and statistical data, while patients might be more interested in how the risk affects their life and in what sense they have to "live the risk" [39]. Communicating cardiovascular risk is particularly complex because of the multiple risk factors causing the disease and because it takes a long time to develop CVDs [36]. CVD has been described as a "sneaky disease" due to the "silent" disease development, where the first symptoms can be a serious or even a deadly event and as an abstract concept that is difficult to understand [40]. Additionally, patients have indicated that they have a hard time understanding the underlying multiplicity of factors that determine their CVD risk such as those currently described in the risk predicting models [41].

Risk perception is influenced by different aspects of cognitive, emotional, social, and cultural aspects that are linked to the individual [42]. In general, lay people use affect heuristics and knowledge built upon personal history and popular sources [43]. The affective system works in an automatic and intuitive

way and is often our first response to a risk, the so-called affective heuristic. Images in our minds are associated with the feeling of good or bad and influenced by memories and experiences [44]. Affect heuristics influence individuals' judgement of benefits and risks e.g., if we enjoy drinking wine, we are more likely to dismiss the risks involved [45]. If a risk is easy to remember or imagine, then we will perceive the risk as higher, which is called availability heuristic [46].

On the whole, people perceive themselves to be at less risk of a negative event and more likely to experience a positive event than the average person [47]. This tendency is called "optimistic bias" and has a cognitive and a motivational source [48]. The cognitive source includes an inability to see which the same risk factors that affect others will also affect us. Additionally, we often compare ourselves to stereotypical images of a high-risk person. Finally, we use available knowledge of the risk, in terms of our own experiences. The influence of the optimistic bias will be reduced if a person has his or her own experiences of the risk [49, 50]. It is common that individuals underestimate their CVD risk, which may constitute an obstacle for prevention, since patients that accurately perceived their risk as high reported higher compliance with secondary prevention interventions [51]. According to the *Health Belief Model,* the individual's perceived susceptibility of risk is an important aspect explaining health behavior [52] and is therefore important to consider when preventing and treating cardiovascular diseases.

Certain characteristics of a risk influence how it is perceived. These are voluntariness, immediacy of an event (time between exposure and event), knowledge of the risk, and control (can it be prevented by the individual). Others are newness, catastrophic-chronic (does it kill one at a time or many at once), if it is common or dreaded, and the severity of its consequences (how fatal is it) [53]. Our lifestyle is somewhat voluntary and reflects how we prefer to live our lives. Most people's lives include risk factors (e.g., unhealthy diet or smoking) and protective factors (e.g., regular exercise), and it is more common for people to consider the positive factors more while disregarding the negative factors. Furthermore, the sacrifices you make regarding your lifestyle today will (perhaps) benefit your health in the future, providing an uneven balance between cost-benefit in the short- and long-term perspective.

It was previously believed that men and women perceived their risks differently, but studies have disproved this theory [54]. The differences between men and women could actually be traced to differences in socioeconomic factors and perceived vulnerability, which are known to affect a person's power to control risks [55]. Immigrants perceived their risk as higher compared to native Swedes in a Swedish study from 2005. The authors saw ethnicity as a marker for inequality in Sweden, putting individuals with a foreign background in a more vulnerable situation. Different social groups vary regarding actual and perceived exposure to risk as well as in the control they possess over it [56]. Vulnerability is often associated with being exposed to multiple

risk factors, where interaction effects might be present. Considering single risk factors only might therefore be an inadequate way of explaining risk perception [57].

Health literacy is also an important factor to consider when explaining risk perception. It reflects a person's cognitive and social skills to access, understand, appraise, and apply health-related information [58, 59]. Health literacy matters when the individual interprets and value risk information, and is therefore highly relevant when studying risk perception and risk information. Closely related to literacy is numeracy, which is the ability to understand and use numbers in daily life. In health care, numeracy related tasks can be about interpreting the meaning of blood pressure figures, and in daily life, it can affect the interpretation of nutrition information [60].

The patient's and public's perspective

Empowerment and informed decision-making

Doctors have previously been viewed as the only expert that should make all the decisions. However, the patient's role in managing chronic diseases is essential since prevention and much of the care of chronic disease take place at home, where health care professionals are not present. The focus and importance of self-management of patients with a chronic disease is therefore inevitable. Patients are experts in their disease and how to manage it in their daily lives and should therefore be seen and treated as partners [61].

The shift from paternalistic health care highlighted patient autonomy and participation. The autonomy and integrity of the patient have been strengthened in recent years through the Swedish Patient Act (2014:8212). This law aims to strengthen and clarify the patient's position in health care activities and to promote the patient's integrity, self-determination, and participation. It states that the patient has the right to information about his/her health condition, risks involved in treatments, and methods to prevent illness or injury.

Autonomy refers to the ability to be self-determinant without interference from others and without limitations to meaningful choice, according to a self-chosen plan. Autonomy is the capacity to make informed choices, which is dependent on sufficient understanding, a capacity of deliberation, and specific capabilities needed for self-management. Respect for a person's autonomy comes from Kant's recognition that "all persons have unconditional worth and a capacity to determine his or her own moral destiny." Therefore, health care and research projects should respectfully disclose information that ensures understanding and voluntariness to enable autonomous decision-making [62].

The participatory models of health care that aim to increase the autonomy and power of patients have introduced concepts like empowerment and shared

decision-making (SDM). Both these concepts are related to each other, striving to make patients take part in their own care. The term SDM refers to clinical situations and the process of communication and deliberation during the patient-provider encounter. The provider shares expertise about the patient's condition and about the risks, benefits, and consequences of available treatment options, and the patient shares information about his/her goals, values, and preferences for treatment [63]. Informed decisions, on the other hand, do not need to involve a clinician nor occur in a clinical setting; instead, there can be a distance between the expert providing the information and the decision-maker [32].

The concept of empowerment evolved from the social action and the self-help movements of the 1960s and 1970s. The empowerment movement was as a reaction to oppression and inequality in society and therefore has a political dimension that revolves around power. The Ottawa Charter for Health Promotion (1986) made empowerment a key issue of health promotion. The charter states that empowerment is achieved through self-help and social support, strengthening public participation, access to information, and opportunities for making healthy choices [64]. Empowerment is defined by Nutbeam and Kickbush as *"a process through which people gain greater control over decisions and actions affecting their health"* [65]. However, many other definitions co-exist. A review from 2015 found 19 different measures, including 38 constructs used to measure empowerment, many of which focus on self-management of chronic diseases [66]. In the enabling process of empowering, individuals obtain knowledge, capabilities, and resources to exercise control and self-management to make informed decisions [67]. Health care professionals can empower individuals, but individuals can also empower themselves. Patient empowerment strategies rest on the assumption that empowered patients will be better at self-management and in making rational decisions to maximize their health [63]. It is also assumed that individuals who are empowered are healthier than those who are not. Hence, the use of health care services will be optimized and the financial burden decreased [61, 63, 67]. Information about risks and benefits is essential in order to empower individuals to make informed choices.

Benefits and harms of risk communication

Ethical principles are moral norms that can help to guide and evaluate the conduct and decisions in public health and medicine. Beauchamp and Childress principles' (2013) of biomedical ethics describe four guiding principles that are commonly used in policy documents and health assessment frameworks: non-maleficence, beneficence, autonomy, and justice. These principles must be balanced when making decisions about the public's and the individu-

als' health [62] and are also important to consider when evaluating an intervention such as risk communication. These principles are reflected in the Swedish Health and Medical Service Act (1982:763), which further increases their legitimacy on a national level. The principle of non-maleficence refers to the obligation of not harming anyone else and thereby depriving others of a good life and also includes the risk of harm. The principle of beneficence refers to acting for the benefit of others and involves acts of mercy and kindness and the rule of preventing harm from occurring to others.

Disease outcomes may be unrealistic for evaluating the benefits and harms of risk communication, since health behavior is influenced by structural and social factors as well as market forces and therefore a major challenge for the individual [68]. Furthermore, disease outcomes and lifestyle changes are goals set from a provider perspective but may not be seen as benefits to individual. The receiver of risk communication might value other factors besides health outcomes, connected to the process of providing the information, such as costs, readability, and support. The public's perspectives of benefits and harms of risk information are important to include as outcomes when evaluating an intervention since they are the ones affected by it and therefore should have a say about its value.

With the shift toward greater autonomy for patients, the goal of risk communication also changed from improving the populations' health to enabling people to make informed choices, consistent with their preferences and values regardless of the outcome [39]. Adequate risk communication should contain information needed for effective decision-making; therefore, the information should be accessible and comprehensible. However, not all individuals have the same capacities to understand and act on risk information, e.g., due to shortcomings in risk presentation, low health literacy or lack of material resources or social support. Therefore, the risk information might only be useful for already privileged individuals and thereby contribute even more to the inequities in health. This is contrary to the principle of justice, which reflects on what is fair in terms of distribution of health and access to health care.

Risk information introduces the choice to act on it, but it also induces implicit expectations to act in a normative way [69]. Since CVDs are, to great extent, caused by modifiable risk factors, a person's lifestyle choices can be perceived as being the individual's own responsibility, and in extension, it would mean that the individual is to blame for his or her own CVD risk level. This idea can lead to the person feeling stigmatized and guilty [69]. For instance, if an obese person receives information about risk factors for CVD and at the same time receives recommendations about losing weight, the obesity is pointed out as the cause of the person's health problems, which the person might feel he or she brought on him or herself. This may be perceived as a personal failure for not being able to meet the expectations of society. Risk information can also potentially cause mental distress [70-72], about something that may not happen.

Preventive medicine may also run the risk of being arrogant [73] and self-righteous [74]. This is because experts address healthy asymptomatic individuals with recommendations on what to do to stay healthy and thereby claim to know what is best for them. Furthermore, there is an assertiveness about the premises that the interventions will do more good than harm, while the uncertainty of facts and probabilities regarding the risk and the effectiveness of the intervention are not emphasized enough [73, 74]. These tendencies can damage the trust held by the public, which influences the efficiency of the interventions and the legitimacy of experts and institutions [35]. Professionals should therefore seek to balance the goals of promoting health and respecting the variety of views and values among the population, by showing more compassion and humility [74]. This can be accomplished by empathizing with the target group and acknowledging the validity of their emotions and concerns. To do so requires active listening and taking their perspective into account [35].

Investigating the public's perspective

The public's (or patient's) perspective of CVD risk communication can be assessed in numerous ways. The various methods answer different types of research questions and can therefore be useful in different situations. It can be useful to start with explorative qualitative methods using open-ended questions and interactive discussions such as interviews, focus groups, and workshops. Here, the participants have the opportunity to raise questions that they themselves find relevant, instead of being limited by pre-defined questions in a questionnaire. It is, for instance, crucial to explore the existing beliefs and knowledge of the target population before the risk information is designed, so that the communication can be connected to these. Qualitative interviews can assess how people intuitively think and make sense of a topic. It can help to determine the target group's beliefs of the and identify knowledge gaps and misconceptions and what affects the optimistic bias. The prevalence of the mapped perceptions can be further investigated using surveys [38].

The public's perspective is also required to capture how the risk communication affects the subjective psychosocial dimensions of health. Outcomes that are relevant to patients and based upon their own perceptions and assessments are referred to as Patient Reported Outcomes (PRO). These are, per definition, outcomes directly reported from the patient before, during, and/or after an intervention, without any interpretation from a clinician. By identifying the public's view of the benefits and harms of the risk information, the goals of the intervention will be clarified. This will be helpful when designing and evaluating the risk communication. PROs are increasingly being requested by health authorities, regulatory agencies, and Health Technology Assessment

bodies (HTA) to evaluate the quality of health care services, medical treatments, and to guide physicians in daily practice [75]. Commonly used PRO instruments relate to e.g., symptoms (pain, fatigue), physical function (self-care, abilities, and mobility) psychological function (distress, anxiety, well-being, and coping), and health-related quality of life (HRQL) [75].

While PROs are very helpful in assessing specific outcomes directly from an individual, a PRO does not provide any information about how the individual values this specific outcome in relation to other outcomes or risk communication elements. That is something that a preference study can answer. The US Food and Drug Administration (FDA) defines Patient Preference Information (PPI) as "*qualitative or quantitative assessments of the relative desirability or acceptability to patients of specified alternatives or choices among outcomes or other attributes that differ among alternative health interventions [76].*" Several methods can be used to elicit public preferences, both qualitative and quantitative [77, 78]. The quantitative methods include ranking-, rating-, and choice-based techniques [79]. PPI is particularly useful in preference sensitive decisions. These are situations where people's views about risk-benefit trade-offs vary within the target population or differ from the health care professionals, or when multiple options exist and no option is clearly superior for all participants. PPI helps to identify the most important characteristics from a user perspective and to assess the relative importance of these characteristics [80]. There are various quantitative methods to elicit patient's preferences, both revealed and stated preferences, while qualitative research can help to understand how individuals reason when making trade-offs. Revealed preferences are obtained from actual observed choices made by the study population but are limited to treatments and interventions that are available on the market. These choices can be biased due to limited market alternatives. Stated preferences are obtained by presenting hypothetical but realistic choices or valuation exercises to the participant [81].

Rationale of this thesis

Many people underestimate their CVD risk, which can constitute an obstacle for prevention. Since the development of CVDs is silent and symptom free, health checkups are necessary to get feedback about the CVD risk of asymptomatic individuals. Risk communication can lead to benefits, in terms of informed choices and risk reduction since CVDs, to a large extent, are caused by modifiable risk factors. However, the risk information itself can bring worries about something that might not actually happen (not all people with increased risk will actually develop CVD). Furthermore, individuals struggle to understand cardiovascular risk information. Development within risk prediction and digital health informatics will increase the amount of personal health information available to the public and lead to demands on optimized risk communication since risk communication, is useless if the target group does not benefit from it.

Therefore, risk communication needs to be improved, so that it meets the needs and preferences of the recipients, builds on their pre-conceptions, and respects people's values and concerns. However, such improvements can only be made by listening more carefully to the individuals' perspectives, in terms of how they interpret risk, how the personal health information is impacting them, and what preferences they have regarding risk information. Elicitation of preferences may play an important role in order to gain knowledge about needs, as well as the benefits and harms involved, when communicating CV risk. It may also offer constructive suggestions that hopefully can improve risk communication and thereby increase uptake rates and satisfaction with health checkups.

Overall aim of the thesis

The overall aim of the thesis is to investigate the publics' perspective of cardiovascular risk information through a multi-method approach, including how individuals perceive risk, factors affecting underestimation of risk, how CVD risk communication affects individuals' psychosocial health, and their preferences for risk communication.

Specific aims

I   The aim of study I was to explore research participants' (adults, age 50–65) perceptions of receiving cardiovascular risk information.

II   The aim of study II was to investigate change in mental distress among research participants after undergoing a cardiovascular risk assessment and receiving individual test results.

III   The aim of study III was to investigate the associations between I) general health and II) family history of myocardial infarction (MI) and the underestimation of perceived cardiovascular risk, and if the participants' calculated risk modifies that association.

IV   The aim of study IV was to investigate the preferences of the general population regarding the communication of health checkup results. Furthermore, to investigate preference heterogeneity and the predicted uptake of several health checkups implementation scenarios.

Methods

The conducted studies have both a qualitative and a quantitative approach. An overview of the studies is presented in Table 1.

Table 1. Overview of the studies

Study	Study 1	Study II	Study III	Study IV
Design	Qualitative, explorative	Before-after study	Cross-sectional	Cross-sectional
Data collection	Focus group interviews	Questionnaire	Questionnaire	Questionnaire with a discrete choice experiment
Participants	31 SCAPIS research participants	434 SCAPIS research participants	384 SCAPIS research participants	423 men and women, randomly selected from the Swedish population
Analysis	Qualitative content analysis	Paired T-test Multiple linear regression	Binary logistic Regression, RERI	MNL log. reg. with latent class analysis, Relative importance, predicted uptake
Outcomes	Perceptions and attitudes	Worry, Anxiety, Depression, Health-related quality of life	Underestimation of self-perceived CV risk	Preferences for CV risk communication

Setting for studies I–III

The aim of the Swedish Cardiopulmonary Study (SCAPIS) was to investigate disease mechanisms to improve risk prediction and drug targeting of cardio-pulmonary diseases and chronic obstructive pulmonary disease (COPD). This can be achieved by thorough health examinations that combine the use of new imaging technologies and epidemiological analyses within a cohort of 30,000 men and women who are randomly selected from the Swedish population and referred to six different study sites in Sweden. Through linkage to national registers, it will be possible to follow-up on aspects such as cause of death, hospitalization, and the participants' living conditions. The inclusion criteria for participation in SCAPIS were men and women, age 50–64, and being able to understand Swedish.

The health examinations in SCAPIS were comprehensive and included computed tomography (CT) angiography, high-resolution ultrasound, clinical measurements, anthropometry, blood sampling, and questionnaires. After completing the baseline examinations, all participants received a written re-port of some of the test results e.g., waist circumstance, Body Mass Index (BMI), blood pressure and heart rate. In their electronically accessible health records, the participants could find test results regarding the coronary artery imaging, and the cholesterol and glucose levels. The results were presented one by one as numerical values. In some cases, reference levels were provided. No total risk score or overall evaluation was provided. In the case of clinically relevant findings, participants were referred to either a primary health care center (PHCC) or specialized care, where they received routine care [1]. For information about Patient Accessible Electronic Health Records in Sweden, see Hägglund & Scandurra 2017 [82].

All participants in studies I–III had participated in SCAPIS, for which they were randomly selected from the municipality of Uppsala and invited to par-ticipate. Uppsala is a region that does not offer subsidized general health checkups to their citizens.

Study I

This was an explorative qualitative study where focus group discussions were used to investigate perceptions and experiences of the participants.

Participants

The were 31participants in total, with 16 women and 15 men. All had partici-pated in SCAPIS, and undergone through examinations at the test center in Uppsala between March and September 2018.

Procedure

An invitation to participate in the focus group interviews was sent out by e-mail, describing the study and how the interviews were going to be conducted. Individuals who were willing to participate were consecutively scheduled for one of the interviews. When scheduling the interviews, we strived to achieve an equal number of men and women in the groups. No incentives were offered for their participation. Five focus group interviews were conducted, and each interview comprised of four–eight participants. The interviews were moderated by the first author and assisted by an observer. They were conducted in Swedish and lasted between 52–76 minutes. The participants were asked to fill out a survey before the interview started, consisting of background questions including age, sex, education level, time since receiving test results, referral, and risk perception.

The semi-structured interview guide used in the interviews included open-ended questions with themes revolving around the comprehensiveness of the test results and its impact on the participants' lives (Appendix 1). Probing questions were asked to explore the participants' perceptions in depth and facilitate a debate. Before starting the discussion, participants were encouraged to speak freely and to address each other directly. At the end of each interview, the moderator summarized the discussion and asked for verification and clarification from the participants. Data collection was concluded after the fifth interview since the data were considered saturated [83]. The interviews were audio-taped and transcribed verbatim.

Data analysis

The transcripts were analyzed with an inductive approach using qualitative content analysis [84]. The transcripts were read through several times to obtain a sense of the whole and to become familiar with the data. While reading, codes were written in the margin, labeling different aspects of the content. The codes were sorted into a coding sheet in Excel and grouped together into different categories by comparing differences and similarities. Through interpretation, it was decided which codes belonged with each other, leading to abstraction of the text. The material was condensed by reducing duplicates and collapsed by merging similar categories. All categories were given a name describing the characteristics of the content [85]. The initial analysis of the manuscripts was conducted by ÅG and ATH. Thereafter, all authors discussed the classifications of the categories and sub-categories until consensus was reached.

Studies II and III

Studies II and III are based on the same data collection, using the same survey. However, some baseline measures were repeated by a follow-up survey in study II.

Data collection

The data collection was an add-on study to SCAPIS enabled by the opportunity to add questions to the original SCAPIS web-based questionnaire, for convenience reasons during spring 2017. Based on power calculations, 615 participants deemed sufficient for the analysis. After 615 participants had responded to the extended questionnaire, the add-on questions were removed. The additional questions included worries about experiencing a myocardial infarction, mental health, health literacy, numeracy, and risk perception. The SCAPIS data collection included a web-based survey, which the research participants responded to in between their first and second visit to the test site. The survey comprised of multiple questions regarding e.g., the participants' educational level, medical history, stress, lifestyle, and health-related quality of life. Three months after the participants' first visit to the test center, an online follow-up survey, included repeated questions about health-related quality of life, and mental distress but also questions related to their test results (diagnosis and referral), was sent to everyone who provided their e-mail address (n=576). Two reminders were sent out at approximately two-week intervals. The questionnaire was complemented with data from the health examinations (total cholesterol, systolic blood pressure, waist circumference, and BMI).

Worries about experiencing a myocardial infarction ("Are you worried about having a heart attack?") were assessed on a 5-point scale, ranging from not worried at all to extremely worried. Mental health was assessed by the Hospital Anxiety and Depression Scale (HADS). It consists of 14 items, which are divided into an anxiety subscale (HADS-A) and a depression subscale (HADS-D). The cut-off levels are: 0–7 normal, 8–10 borderline, and 11–21 abnormal [86]. HRQL was assessed by Short form health survey (SF-12). The twelve items were combined into a mental component summary (MCS) and a physical component summary (PCS), each expressed by a value between 0–100, where 100 represents excellent health [87].

Self-perceived risk was assessed on a 7-point Likert scale using the question "Compared to other people of the same age and sex as you, how do you perceive your risk of having a heart attack in the next ten years?" General health was assessed through the question "In general, would you say your health is: excellent, very good, good, somewhat good, or poor?" Family history of MI included parents or siblings and was not age-specific. Medical

background was assessed by asking about treatment for or diagnosis of CVD, diabetes, hypertension, or high cholesterol before participating in SCAPIS.

Data analysis Study II

Study II was a before- and after study investigating change in mental distress and HRQL between baseline and follow-up three months later. Exposure related to the type of test result received. Mental distress included disease specific worries about experiencing a myocardial infarction and HADS. Descriptive statistics were performed to describe the study population. Independent t-tests, one-way ANOVA, and Pearson's correlation were used to analyze the differences in mental distress and HRQL between different referral groups and descriptive variables at baseline. To test for differences in mental distress and HRQL between baseline and three months after the risk assessment, paired t-tests were conducted for all dependent variables. The analyses were conducted for the total sample and separately for participants who were referred to either the PHCC or the hospital. Paired t-tests were also conducted separately for participants diagnosed with hypertension, high cholesterol, or coronary artery stenosis. Differences in mental distress between baseline and three months after the risk assessment were further tested in multiple linear regression models. The follow-up measurements of mental distress were used as dependent variables, and the referral group comprised the independent variables, adjusting for baseline measures of psychological factors, age, and health literacy.

Data analysis Study III

Study III was a cross-sectional study investigating the associations of general health and family history of MI with an underestimation of cardiovascular risk. These associations were chosen for investigation since they appeared to influence the participant's self-perceived CV risk and overshadowed other risk factors in the focus group interviews. The calculated risk was assessed using the 2015 version of the Systematic Coronary Risk Estimation (SCORE) [88]. SCORE is used to calculate the ten-year risk of fatal cardiovascular disease for apparently healthy individuals 40–65-years-old, based on sex, age, total cholesterol, systolic blood pressure, and smoking status. The calculated risk is categorized: <1%=low risk, 1-4%=moderate risk, 5-9%=high risk, and >9 %= very high risk. Participants with diabetes type 2 (n=23), established CVD (n=34), systolic blood pressure ≥ 180 (n=2), and total cholesterol >8 mmol/L (n=13) were included in the high-risk group. Women had a calculated risk ranging between 0–3%. The male participants had a calculated risk ranging between 1–10%. Based on the difference in the distribution between men and women and to make the calculated and the self-perceived risks comparable, the participants were divided into three new categories based on the calculated SCORE risk: low (1% for men and 0% for women), moderate (2–4%

for men and 1% for women), or high risk (5–10% for men and 2–3% for women). Based on the distribution of the calculated CVD risk and the self-perceived MI risk, 31% of the participants were classified as underestimating the risk (perceived risk lower than calculated risk), 42% as having an accurate risk perception (perceived risk in agreement with the calculated risk), and 27% as overestimating the risk (perceived risk higher than calculated).

The statistical analyses were restricted to the 526 subjects with complete information on exposures (n=77 missing) and covariates (n=12 missing) and those who were classified as accurate (n=222), underestimated (n=162), or overestimated (n=142) risk perception. The association of I) general health and II) family history, with an underestimation of the CVD risk, was estimated as odds ratios (ORs) and 95% confidence intervals (CI) using logistic regression analyses. A separate analysis was also conducted for overestimating CVD risk. Accurate risk perception was the reference category in all analyses. Confounders were explored and selected based on directed acyclic graphs (DAGs).

Effect modification of the associations by the individual's calculated SCORE risk level was investigated by combining the SCORE with general health or family history into two new categorical variables using a joint reference category in logistic regression [89]. We then calculated the relative excess risk due to interaction (RERI), where a RERI=0 indicates no effect modification [90].

Study IV

Discrete choice experiment

We used a Discrete Choice Experiment (DCE) to determine the publics' preferences for communication of health checkup results. In a DCE, respondents are given a series of 'choice tasks' that consists of at least two alternatives of a specific service or drug treatment. The alternatives are constructed by varying the levels of the characteristics (attributes). The respondents have to choose the alternative that they prefer the most within every choice task. The respondents' preference for an intervention is determined based on their choices in the different choice tasks. This method allows for the estimation of the relative importance of different characteristics of the risk communication and the predicted uptake rate [91, 92].

Procedure

The attributes in the DCE were carefully selected according to previously described procedures [79]. We identified a list of possible attributes based on

previous research [93-105], which were discussed with experts, to help condense it and to ensure that the attributes were consistent with current practice. The remaining attributes were discussed with eight individuals from the study population during three focus group interviews using the Nominal Group Technique [106]. This entails that participants discussed and ranked their five most important attributes and ensured that no important attributes were missing. An additional 53 individuals from a convenience sample ranked all attributes from most to least important. Six attributes were chosen: written results, waiting time, consultation time, and lifestyle recommendations since they were top-ranked and cost and notification method due to their policy relevancy.

NGene 1.0 software was used to generate the design for the DCE, which included 60 unique choice tasks. The choice tasks were divided into four blocks of 15 unique choice tasks. Respondents were randomized to one of the blocks. Each choice task consisted of two alternatives, so respondents were forced to choose between alternatives for health checkups. Thereafter, respondents were asked if they would actually participate in the selected health checkup in real life or whether they preferred to opt-out (dual response design). An example of a choice task is presented in Figure 1.

Besides the DCE, the web-based survey included information about the attributes and levels and additional questions including health literacy, which were measured using the validated Swedish Functional Health Literacy Scale [107]. The context of the health checkup in the DCE was described as a general health checkup conducted by a primary health care center that invited the public and where traditional tests were included (e.g., glucose, blood lipids, and blood pressure). To test for wording of the survey and to ensure that the respondents grasped the DCE, the survey was pilot tested with respondents from the target population (n=32). Three think-aloud interviews were also conducted. The pilot test resulted in minor changes to the wording.

Which one of the following checkups do you prefer, Health checkup A or Health checkup B? (1 of 15)	
Health checkup A	**Health checkup B**
Written test results: • Numerical lab values • Every day language • Overall assessment	**Written test results:** • Numerical lab values
How you will be notified: • Through your electronic health record	**How you will be notified:** • Through your electronic health record • and a letter
Waiting time for your test results: 2 weeks	**Waiting time for your test results:** 2 days
Lifestyle recommendations: Yes, it is included	**Lifestyle recommendations:** No, it is not included
Consultation with a medically trained person: 30 minutes	**Consultation with a medically trained person:** 0 minutes
This will cost you: 600 SEK	**This will cost you:** 150 SEK
☐	☐
Would you participate in a health checkup similair to the one you chose, if you received an invitation in real life?	
Yes, I would participate in real life ☐	**No**, I would not participate in real life ☐

Figure 1. Example of choice task (translated from Swedish to English)

Participants

A random sample of men and women, aged 40–70 (n=1,650), was drawn from the Swedish population by Statens personadressregister, SPAR (*English: the state's personal address register*), a register that includes all persons who are registered as a resident in Sweden. The number of respondents needed for the DCE is dependent on the number of choice tasks, the number of alternatives in a choice set, and largest number of levels in any attribute. Based on previously conducted and published DCE studies, a final number of 200–300 completed questionnaires was deemed sufficient [108]. Based on previous population studies in Sweden that often have a quite low response rate, we expected to have the same for our study. Therefore, we invited considerably more people than we expected to respond to ensure that we received enough responses.

Data analysis

Descriptive statistics are presented with mean and standard deviation for continuous variables and as frequencies and percentages for categorical variables. The statistical analyses were restricted to subjects who completed a minimum of 13 out of 15 choice tasks (i.e., <10% missing data on their choice tasks).

A latent class analysis was performed to investigate not only the respondents' preferences but also the preference heterogeneity. The model estimates the respondents' unobserved "latent" preferences by using the data to identify segments of the sample with similar choice patterns [109]. As part of the latent class model, a class assignment model was fitted to predict the class membership based on personal characteristics. In this study, we tested class membership predictions for: sex, age, educational level, HL, civil status, country of birth, economic constrains, lifestyle, medical history, risk perception, family history of myocardial infarction (MI), and self-perceived general health.

The relative importance of the attributes was calculated and compared across the different classes. Predicted uptake was calculated for several hypothetical health checkup scenarios, using $\frac{1}{(1+exp^{-V})}$, both for each latent class and as an average uptake. Based on existing health checkups in Sweden, a "realistic scenario" for the implementation of a national health checkup was formulated: cost 30 euro; 30 minutes consultation time; a letter, together with accessing the results online; two weeks waiting time; written in everyday words; and lifestyle recommendations included. Predicted uptake was then calculated for this realistic scenario as well as for several scenarios with a change in one of the attribute levels. By comparing the uptake rates of the different scenarios, the effect of changing one attribute at a time on the predicted uptake of the "realistic scenario" was estimated. Based on the estimates of the latent class model, the least and most preferred health check scenarios were determined.

Ethical considerations

Ethical approval was granted for all studies in the thesis, by the Uppsala Regional Ethical Review Board (Reg. no. 2016/256) and the Swedish Ethical Review Authority (dnr:2019:03843).

The studies in this thesis question individuals about CVD risk and health. As these questions relate to life and death, they may stir up and trigger emotions connected to previous events in people's life.

In study I, the participants were informed in the invitation letter about the aim of the study, how the interviews would be conducted, and how data would be managed. Prior to the interviews commencing, the participants were informed again, about the study both orally and in writing, whereby the they signed a written consent form. The researcher emphasized that the participants could end their participation at any time during the discussions. In the focus group discussions, no names or personal identification information were obtained about the individuals. The data were presented in a way that no individuals could be identified. However, a focus group setting is special, in the sense that the participants not only share information about themselves with the researcher but also with the other participants in the room. Focus groups interviews are based on the interaction between the participants; thus, it is difficult to know beforehand what subjects will arise and what the participants will share with the group. The method is positive in that it allows participants to raise questions about a subject that they find important, instead of being limited by the researchers' pre-defined questions in a questionnaire. During the interviews, stories including grief and worries were shared even though the researcher did not directly raise such questions. The fact that they chose to share this kind of information could be a sign that they felt comfortable and safe within the group.

The respondents of the questionnaires gave their consent to participate by answering the survey. They had received written information about the studies prior to that. In study IV, much effort was put into the invitation letter, aiming to write it in an everyday language using lay terms. Even though the invitation letter said that participation was optional, there were individuals who contacted the first author (ÅG), not understanding what the invitation was about, whether participation was optional, and if it involved any kind of invoice. Therefore, there is a risk that a questionnaire study may cause worries when people do not understand the information received or cause irritation due to the repeated the reminders. Just like in the interviews, the questions in the survey might be perceived as intrusive; therefore, whenever possible, there was an option in the questionnaire to skip the question. The collected data were subsequently anonymized, and no individuals can be identified in the final presentation of the results.

Summary of findings

Study I: Exploring research participants' perceptions of cardiovascular risk information – Room for improvement and empowerment

Two-thirds of the participants had a university degree, and 28 of the participants were born in Sweden. The mean age of the participants was 61 years. Ten participants had received abnormal findings and were referred to either a primary health care center or to the hospital. The analysis resulted in four main categories, each of which consisted of several sub-categories (Table 2).

Table 2. *Categories and Sub-categories*

The complexity of cardiovascular risk	Insufficient presentation of test results	Reactions to the test results	Health examinations provide confirmation
Relying on physical signs	Lacking understanding	Worry, relief, and gratitude	Relevance increases with age
Simplified and conflicting beliefs	Only allowing dichotomous interpretations Lack of recommendations	Passive waiting or action taken	Current lifestyle: Confirmed or questioned

The Complexity of cardiovascular risk

Relying on physical signs
Participants' personal risk was largely perceived based on how they felt in general. They relied on their body to indicate any problems and therefore expected normal test results in the absence of such an indication.

Simplified and conflicting beliefs
Participants' perception of CV risk was occasionally simplified into an "either/or" approach that disregarded multifactorial associations, e.g., you are healthy if you either do every-thing right or have good genes. Cardiovascular diseases were perceived as unpredictable and uncontrollable, especially by individuals who had personal experiences. They brought up atypical cases of individuals who either practiced a healthy lifestyle but still had a heart infarction, or vice versa, making them doubt the significance of known risk factors.

Family history of cardiovascular diseases was repeatedly raised as an important CV risk factor.

Insufficient presentation of results

Lack of understanding

The participants perceived the test results as being difficult to understand, since they were written using technical language that contained many medical terms; moreover, they did not understand what the test was intended to show in the first place. The test results were reported separately, and the participants assumed they were all associated with each other although they could not understand how. They therefore expressed a need for a qualified assessment of the overall picture and a personal comment on their specific situation. The participants expressed that they had many remaining questions and wanted to discuss their results with a physician. Participants who were referred were automatically given this opportunity. However, many of the participants who were not referred did in fact turn to someone medically trained for formal or informal help with interpreting the test results, such as a family member or their physician.

Only allowing dichotomous interpretations

When the participants did not understand the results, they relied on the fact that they would hear from the health services if something was wrong. This meant that the outcome (referral or not) was interpreted in a dichotomous way, as either good or bad, and not the values themselves. Some were interested in knowing about their risk presented as a continuum and wondered if they were close or far from the cut-off value. They were also interested in knowing about their risk, in relation to others and wondered what was "normal" or "common" for their age.

Lack of recommendations

Many participants wanted recommendations on what to do in order to reduce their risk and improve their health. They also wanted guidance on how to navigate the healthcare system and where to seek further care. They perceived it as their own responsibility to take the necessary action, but required guidance from health services in order to do so.

Reactions to the test results

Worries, relief, and gratitude

Participants who received normal test results felt reassured that everything was okay and expressed joy and a sense of relief. Some were able to let go of their worries, especially participants who had a previous experience with

CVD. Reading something that they did not understand caused some participants to worry, e.g., test results regarding arteriosclerosis. One woman asked a nurse who worked with the CT scan what she could expect the results to be. The nurse then prepared her for a possible answer while also trying to normalize the risk. Another woman had the experience of her cholesterol level being treated as "normal" in previous health examinations and as "abnormal" and in need of corrective measures in the SCAPIS health examination. This made her worried and uncertain about what to think regarding her risk level.

Being referred to the hospital due to coronary artery stenosis, caused some of the participants to be worried, while others felt healthy and therefore did not worry. In their meeting with the physician, participants could receive emotional support and help with managing their worries. They felt safe being under the supervision of the healthcare system and expressed gratitude with regard to knowing about their condition.

Passive waiting or actions taken
The measures taken to treat the participants' coronary artery stenosis had different implications for their daily lives. One man was told to wait passively for any impairments because of his condition, while also slowing down his current active lifestyle. This left him frustrated and unable to act, and resulted in him thinking about his condition daily and paying frequent attention to his physical symptoms. Another man had a stent placed in his arteries due to findings in SCAPIS. This left him feeling happy and grateful for "getting something" that could potentially prolong his life. He felt that his problem was fixed and his risk was reduced.

Health examinations provide confirmation

The relevance increases with age
The participants expressed a positive attitude toward health examinations, no matter what the outcome. A normal test result was seen as a confirmation of being healthy, while an abnormal test result was perceived as an opportunity for prevention and treatment. Health examinations were described as gaining relevance with increasing age, when symptoms and illnesses become visible and health is no longer taken for granted.

Current lifestyle: confirmed or questioned
The results were used for self-reflection on participants' current lifestyle. Normal test results led to the perception that no lifestyle changes were necessary. Participants with abnormal results questioned their current lifestyle and felt that they were not doing enough. Receiving abnormal results was described as the "trigger" required to make necessary changes, something for which they expressed gratitude.

Study II: Short-term mental distress in research participants after receiving cardiovascular risk information

In total 435 participants answered the follow-up questionnaire. Half of the participants (50.2%) had a university education, 53% were women, and the mean age was 58 years. Twenty percent of the participants were referred to a PHCC and 14.3% to the hospital for specialized care. Seventeen participants reported being diagnosed with coronary artery stenosis, 19 with hypertension, and 10 with high cholesterol.

For participants who were not referred or referred to a PHCC, no statistically significant differences were found for any of the outcomes between baseline and after three months. For participants referred to the hospital, there was an increase in worry and anxiety, and a decrease in MCS (indicating a deterioration in mental health). Paired t-tests were also conducted for all outcome variables based on a diagnosis of high cholesterol, hypertension, or coronary artery stenosis. There were changes in the level of worry, anxiety, and MCS for participants diagnosed with coronary artery stenosis, one of the conditions for hospital referral (Table 3).

Table 3. *Worry, HADS, and HRQL at baseline and after three months. Difference tested with paired t-tests.*

Psychological factors		N 434	Baseline Mean (SD)	After 3 months Mean (SD)
Worries about ex-periencing a my-ocardial infarc-tion	Total	408	1.6 (.7)	1.7 (.7)
	Not referred	266	1.6 (.7)	1.6 (.7)
	Referred PHCC	82	1.6 (.6)	1.7 (.6)
	Referred hospital*	52	1.8 (.7)	2.0 (.8)
SF-12 PCS[a]	Total	418	50.7 (7.7)	50.5 (7.5)
	Not referred	271	50.9 (7.4)	50.9 (7.0)
	Referred PHCC	84	50.7 (8.3)	50.1 (8.0)
	Referred hospital	53	49.6 (8.5)	49.3 (7.5)
SF-12 MCS[b]	Total	418	51.8 (9.1)	51.1 (10.3)
	Not referred	271	51.8 (9.0)	51.5 (9.6)
	Referred PHCC	84	52.0 (8.6)	51.5 (10.0)
	Referred hospital*	53	52.0 (9.1)	49.6(11.0)
HADS[c] Anxiety score	Total	416	4.4 (3.5)	4.5 (3.6)
	Not referred	271	4.4 (3.6)	4.4 (3.6)
	Referred PHCC	83	4.0 (3.1)	4.0 (3.2)
	Referred hospital*	52	4.7 (3.1)	5.4 (3.4)
HADS Depres-sion score	Total	416	3.3 (2.9)	3.3 (2.9)
	Not referred	271	3.3 (3.1)	3.2 (2.9)
	Referred PHCC	83	3.2 (2.6)	3.4 (2.7)
	Referred hospital	52	3.6 (2.4)	3.8 (2.9)

*Indicates statistically significant difference. [a]Physical omponent summary [b]Mental component summary [c]Hospital anxiety and depression scale

Associations between the change in mental distress after three months and referral groups after three months were tested in multiple linear regression models, adjusting for age and health literacy level. Diagnosis of coronary artery stenosis was also adjusted for, since this was one reason for referral to the hospital in SCAPIS, and because there was a significant change in the paired

t-test analysis. No associations were observed in the regression models between change in worry, anxiety, and MCS and referral were when adjusting for age, health literacy, and diagnosis with coronary artery stenosis. There was an association between change in worry and diagnosis with coronary artery stenosis (p<0.000). There was also an association between change in anxiety and diagnosis with coronary artery stenosis (p=0.03). No associations were observed between referral or diagnosis and MCS, PCS, or depression.

Study III: Good general health and lack of family history influence the underestimation of cardiovascular risk- a cross sectional study

The study population mainly comprised highly educated individuals born in Sweden, and had a slightly higher share of women. Those with excellent or very good health were more likely to be highly educated, have higher health literacy, and have fewer CVD risk factors. Participants with a family history of MI more often perceived their risk as higher compared to participants without family history.

The associations of I) general health and II) family history with an underestimation of risk were estimated in separate logistic regressions models (Table 4). Participants with a very good or excellent self-perceived general health were more likely to underestimate their cardiovascular risk compared to participants with bad or fairly good general health (adjusted OR 2.60, 95% CI 1.10–6.16). Participants without a family history of CVD were more likely to underestimate their cardiovascular risk compared with participants without a family history (adjusted OR 2.27, 95% CI 1.24–4.18). We also estimated the associations of general health and family history of MI on the overestimation of cardiovascular risk. Those with very good general health compared with poor/fairly good health, (OR 0.26, 95% CI 0.12–0.55), and those without family history of CVD compared with a family history (OR 0.44, 95% CI 0.25–0.76) were less likely to overestimate their CV risk (Table 4).

Table 4. *The association of general health and family history with an underestimation and overestimation of cardiovascular risk.*

Underestimation of CVD risk

	N	N underes-timating	Model 1 OR (95% CI)	Model 2 OR (95% CI)
General health				
Poor/fairly good	56	17	1.00 (ref)	1.00 (ref)
Good	127	48	1.80 (0.87–3.69)	1.59 (0.68–3.69)
Very good/Excellent	201	97	3.00 (1.51–5.97)	2.60 (1.10–6.16)
Family history				
Yes	83	24	1.00 (ref)	1.00 (ref)
No	301	138	2.33 (132–4.10)	2.27 (1.24–4.18)

Overestimation of CVD risk

	N	N overesti-mating	Model 1 OR (95% CI)	Model 2 OR (95% CI)
General health				
Poor/fairly good	81	42	1.00 (ref)	1.00 (ref)
Good	136	56	0.59 (0.34–1.06)	0.50 (0.25–1.00)
Very good/Excellent	148	44	0.34 (0.19–0.61)	0.26 (0.12–0.55)

Family history				
Yes	109	50	1.00 (ref)	1.00 (ref)
No	256	92	0.54	0.44
			(0.33–0.87)	(0.25–0.76)

Each analysis was restricted to those with the outcome and those with accurate estimation of their cardiovascular risk, N=384 for underestimation and N=365 for overestimation. Model 1 included: age and sex. Model 2 included: age, sex, education, health literacy, numeracy, smoking, physical activity, abdominal obesity, stress, (self-reported) hypertension, high cholesterol, diabetes and CVD. Family history was also included in model 2 for general health. OR: odds ratio, CI: confidence interval

The participants' calculated risk level (SCORE) modified the associations of general health and family history with an underestimation of CVD risk. Thus, the combination of having a high SCORE risk and excellent/very good health (n=14) or no family history (n=33) was associated with a higher likelihood of underestimating cardiovascular risk compared to having estimated a moderate risk. However, the confidence intervals for the estimates of the effect modification were wide, indicating uncertainty in the measurement (RERI: 7.68, 95% CI –9.35-24.71 for excellent/very good health and RERI: 19.01, 95% CI –7.52-45.53 for no family history).

Study IV: Communicating test results from a general health checkup: the public's preferences from a discrete choice experiment survey

In total, 482 respondents started the survey (response rate 29.6%). Thereafter, 59 respondents were excluded from the analysis because they dropped out before the choice tasks (n=36) or dropped out between choice task 1–10 (n=23). The final analysis included 423 individuals. Most respondents were working, living together with a partner, had a university education, and were born in Sweden. A quarter of the respondents were obese, and 30% were diagnosed with or treated for hypertension.

On average, respondents' decision to take part in a health checkup was mostly driven by the associated cost, followed by consultation time, inclusion of lifestyle recommendations, details of written results, waiting time, and notification method. However, there were differences in preferences. The latent class analysis identified three classes. The average probability was 43% of belonging to class 1, while this was 11% for class 2 and 46% for class 3.

Classes 1 and 3 had a negative coefficient on the opt-out alternative (meaning that they were positive to participation), while class 2 was positive to opt-

out (negative to participating). In all classes, cost was the most important attribute considered; with increasing costs, the willingness to take part in the health checkup decreased significantly. All attributes except for waiting time contributed to utility in Class 1, while cost and notification method were the only attributes contributing to the utility of respondents in Class 2. Notification method was the only attribute not contributing to utility in Class 3. Respondents in Class 3 preferred 15 minutes and 30 minutes consultation time, instead of no consultation; written results consisting of numerical values; use of everyday language; an overall assessment instead of only numerical values; and to receive lifestyle recommendations. Additionally, respondents in Classes 1 and 2 preferred receiving their test results by letter, as opposed to only being able to access their results through their electronic health records. Class 3 preferred waiting two days, as opposed to two weeks. Respondents in Classes 1 and 2 were less likely to have sufficient HL compared with respondents in Class 3. The relative importance of each attribute is presented in Figure 2.
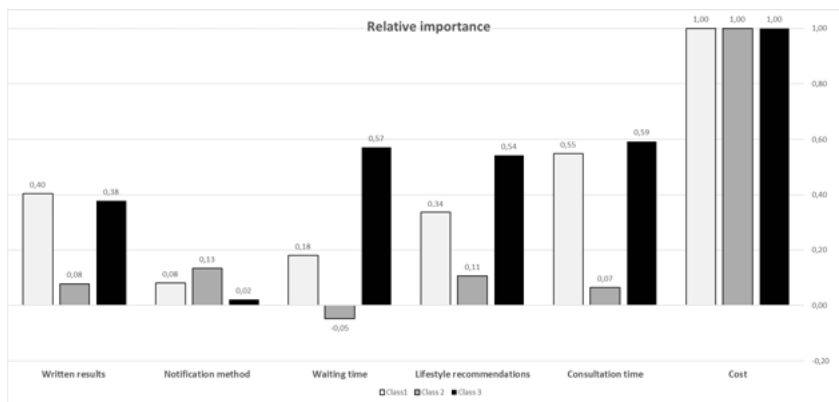

Figure 2. Relative importance of the attributes separate for each class.

On average, the predicted uptake ranged from 7%–88% between least and most preferred scenario, but it varied a lot between the classes (Table 5). The average predicted uptake for the realistic scenario was 66% but when made free of charge, the uptake increased to 75%. The effect of changing one attribute at a time on the predicted uptake of the "realistic scenario" was estimated. Increasing the cost of the health examination and excluding the consultation and lifestyle recommendation, while keeping all other attributes constant, decreased the predicted uptake the most.

Table 5. *Predicted uptake for three implementation scenarios*

	Class 1	Class 2	Class 3	Average
Most preferred: overall written assessment, letter, 2 days waiting time, lifestyle recommendations, 30 min consultation time, free of charge	100%	20%	93%	88%
Least preferred: only numerical information, no letter, 3 weeks waiting time, no lifestyle recommendations, no consultation, € 120	15%	0%	2%	7%
Realistic: everyday language, letter, 2 weeks waiting time, lifestyle recommendations, 30 min consultation time, € 30	98%	5%	50%	66%

Discussion

This thesis approached the research questions with both qualitative and quantitative methods. The studies in this thesis show the usefulness and necessity of using qualitative and quantitative methods in a complementary way. The results from the qualitative interviews guided the analyses and interpretation of the results in the quantitative studies by understanding how individuals reason about the subject. Besides answering its specific aims, this thesis may provide a case study of different ways to capture the patient's or public's perspective.

The public's perspective

Perceptions of cardiovascular risk and risk information

Knowledge about how lay people make sense of CVD risk is needed to be able to adapt the risk communication to the recipient's pre-understanding, bridge knowledge gaps, and avoid misunderstandings. The participants in study I had complex perceptions of CVD risk that included both simplified and conflicting beliefs. Life experiences of their own cardiovascular events or of people close to them made them perceive CVDs as unpredictable and uncontrollable. Some participants referred to atypical cases, friends that did everything right, but still experienced a MI. One man who experienced a MI himself thought that his healthy lifestyle would protect him against CVD. *"It just happens at once, without any indication [...] I had all sorts of normal - I exercised too, but it [the MI] happened."* The perceptions about the unpredictability of CVDs may be an indication that CVD risk communication in society is, in fact, too assertive regarding the effectiveness of preventive measures. This could be improved by including uncertainty to the risk message to a greater extent and emphasizing that preventive measures cannot guarantee protection against CVDs 100%; rather, they only decrease an individual's risk.

A tendency to disregard common risk factors in favor of family history and general health was observed among the participants in the focus groups. Hence, it was hypothesized that this tendency influenced the common phenomenon to underestimate CVD risk and was investigated further in study III.

The associations of I) general health and II) family history with an underestimation of CVD risk were confirmed in study III. Furthermore, it was shown that the associations were independent of factors related to understanding of health information, including health literacy. Poor general health and a family history of CVD have both been associated with high perceived cardiovascular risk in past studies [110-114] and were associated with an underestimation of cardiovascular risk in a U.S. population [115].

The associations of I) general health and II) a family history with an underestimation of CVD risk may be explained by the fact that lay people use their own personal experiences and perceptions when assessing risks [43], which influences availability heuristic to perceive the risk as higher. The availability heuristic is also influenced by predominant social beliefs about causal relationships [46]. Walter et al. (2005) explained perceived risk due to family history beyond causal beliefs, instead as personal life event attached to negative emotions like fear or grief influenced by witnessing the illness or death of a family member [116]. There is also the belief that one can compensate for risky behaviors by engaging in healthy behaviors [117]. Even if individuals are aware of the negative impact of being a smoker, they may believe that they can compensate for the increased risk by being physically active, for example. How individuals feel in general seems to override other existing information regarding risk factors [118]. In a Dutch study from 2011, they found an association between family history and risk perception, but there were weak associations between risk perception and other risk factors. For instance, they found no association between being a smoker and risk perception, even though most participants thought that smoking caused CVDs [113]. This further indicates that the associations cannot be explained merely by the lack of knowledge or ability to understand the risk; rather, it is the inability to apply that knowledge to themselves, which has also been suggested in previous studies [113, 119].

The participants interpreted the implications and meaning of the test results beyond what was actually written. The outcome, in terms of referral or not, was interpreted in a dichotomous way, as either good or bad, and not the values themselves. Normal test results were perceived as a validation of the participants' current lifestyle and that there was no need to make improvements, when the individuals' clinical values might in fact be right below the cut-off limit for being a clinical case. These finding are evident also in studies of perceptions of CV risk [102, 120], and can be an obstacle for the promotion of healthy lifestyle habits of the healthy general population, leaving individuals with a false sense of reassurance [121]. This emphasizes the importance of being explicit about the meaning and implications of the test results to dissuade participants from filling in gaps in the information with inaccuracies.

Needs, desires, and willingness to participate in health checkups

Overall, the SCAPIS participants in study I perceived that the test results from the health examinations were difficult to understand. They requested a qualified assessment of their total risk, in which the different test results were taken into account in order to make sense of their personal risk. The participants that were not referred to a PHCC or a hospital expressed a need for guidance and support from medically trained personnel, to have their results explained to them and to get recommendations on what to do in order to reduce their risk as well as on how to navigate through the healthcare system and find more information. In study IV, besides cost, consultation time was most important when choosing between the health checkups alternatives, which further emphasizes individuals' wish for consultation to discuss the test results. A study of the NHS cardiovascular health checkup in the United Kingdom had similar findings: the participants expressed uncertainty about the implications of their test results and requested guidance from trained medical personnel [102]. These factors constitute obstacles for understanding and making informed choices, which decrease the value of the information.

Understanding of test results is influenced by individuals' health literacy, which relates to an individual's ability to access, understand, appraise, and apply health information and influence the use of health services [122]. In study IV, respondents with a lower HL level were more likely to put greater emphasis on longer consultation time and more comprehensive written results (including an overall assessment), which might be a sign of a need for more support from the health care to utilize the test results. Respondents with a lower HL level also valued receiving a letter with their test results, as opposed to accessing their results online, while respondents with a sufficient HL level did not. The respondents with a sufficient HL level instead valued shorter waiting time and lifestyle recommendations.

In study I, the SCAPIS participants expressed that they valued health examinations since they can provide information about their personal health from a highly trusted source and being offered the possibility to detect and treat illnesses, even if most participants said that they did not expect anything to be wrong. However, this positive attitude toward health examinations may be biased by the fact that only people who agreed to participate in SCAPIS were included in the interviews. The kind of examination offered in SCAPIS included examinations that were new to the participants; thus, participation offered a unique opportunity to undergo these examinations and receive information regarding calcification of coronary arteries, for instance.

These positive attitudes toward participating in health checkups were also found in study IV, where the study sample comprised a random sample of the Swedish population. Nonetheless, the predicted uptake rate ranged between 7–88% from the least preferred to the most preferred health checkup scenario. One group of respondents was very positive to participation and showed a

greater willingness regardless of the conditions of the health checkup. Tailoring the health checkup based on these respondents' preferences will not have a major impact on the average uptake rate. However, since these respondents were more likely to have a low HL, meeting their needs is crucial for the utilization of the test results. The average predicted uptake for a "realistic scenario" (cost 30 euro; 30 minutes consultation time; a letter together with being able to access the results online; two weeks waiting time; written in everyday language; lifestyle recommendations included) in study IV was 66%. To reach the participation rate of >70% as recommended for screening programs by the WHO, namely the "realistic scenario" included in this study, either the cost will need to be reduced, an overall assessment added, or the waiting time decreased. Although cost was the most important factor, it is not sufficient to offer health checkups free-of-charge if other requirements regarding how the test results are communicated are not in place (enough consultation time, lifestyle recommendations, and comprehensive easy to read written results). Cost was the most important factor for all respondents and together with notification method, the only attribute of importance for a minority (11%) group of respondents. This group was consistently negative toward participation and reached a maximum of 20% uptake rate, even in cases where the health checkup was free-of-charge. This indicates that there are other factors not considered in this study, explaining why this group was reluctant to participate.

The impact on psychosocial health

To assess the value of an intervention, it is necessary to investigate the benefits, and harms involved. When it comes to risk communication, a potential harm is mental distress. The results of studies I and II show that most participants did not experience much worry about potentially getting a myocardial infarction prior to the examinations in SCAPIS, perhaps since most of them did not experience any symptoms. Study II showed that there was an increase in worry and anxiety for participants referred to the hospital due to coronary artery stenosis. Some focus group participants also shared that they experienced worry, mainly those who were referred to the hospital, but there were also cases involving raised cholesterol level or reading about calcification in their test results online. However, the participants referred to the hospital expressed that the support and care they encountered from the healthcare professionals were comforting. Preparation before and support after the health examinations are believed to prevent negative emotions triggered by a health examination [123]. For instance, Jorgensen *et al.* did not detect an increase in anxiety among the participants [18], but in their study, both individual- and group counseling were part of the intervention. Therefore, support is an important factor to consider when communicating CVD risk.

It is also possible that the inflicted harms can be judged as acceptable when balanced against the potential benefits of treatment and care permitted by the

detection of risk factors. Furthermore, specific worry has been associated with the intention to take preventive action. Therefore, a degree of disease-specific worry might not be something that should be avoided, but something that may help participants engage in preventive behaviors [124, 125]. However, even in cases when risk is communicated without an increase in mental distress, lack of distress is not enough to consider an intervention as successful, but reflects only an ethical requirement not to do harm. For an intervention to be considered as successful, it should also be possible to measure an increase of something that is beneficial for the individual [126].

In study II, besides mental distress, the impact of CVD risk information on HRQL was measured using SF-12. A decrease in HRQL after receiving test results would have been another way to capture inflicted harm, and an increase would have measured benefit. However, we did not observe any changes in HRQL, positive or negative. Either the risk information did not provide any benefits to the participants (in terms of PRO) or none of the measurements used in study II could capture these benefits. Furthermore, to respect autonomy, risk communication should be designed and evaluated in order to do good, according to what the individual him- or herself perceives as beneficial. It is not clear whether these outcomes matter to the participants.

Empowerment as a framework to measure the impact of CVD risk communication

Based on the findings of study I, the participants valued the confirmation they got from a normal test result, which led to feelings of joy and relief and increased their psychological well-being. They also expressed a desire to learn about themselves, about cardiovascular diseases, CV risk factors, the health system, and the tests included in the examinations to improve their overall understanding. They inquired about where to find more information and support if needed, and recommendations on what to do to manage their health and risk. These aspects represent benefits that matter to the recipients and may therefore be included as important PROs when evaluating the communication of cardiovascular risk information. Many of these are reflected in the components of a specific conceptualization of empowerment used to evaluate genetic risk communication, the Genetic Counseling Outcome Scale (GCOS-24) [127].

GCOS-24 comprises of five dimensions. *Decisional control* is about knowing what options are available for managing the condition and feeling able to make informed decisions. *Cognitive control* is about having sufficient information about the condition, including risks to oneself and one's relatives, and any treatment, prevention, and support available. *Behavior control* is about being able to use the health and social care systems effectively. *Emotional regulation* is about being able to manage one's feelings. *Hope* is about being

able to look to the future and have hope for a fulfilling family life, for oneself, one's family, and/or one's future descendants [128]. This instrument of empowerment is based on qualitative studies that concluded that "respondents value knowledge for its own sake and that patients value feeling in control of their lives and their health even if they do not wish to use that control for engaging in a health behavior change that will maximize their health" [129]. Furthermore, this instrument was designed to evaluate personal risk information and not a treatment, and it addresses asymptomatic individuals who do not know if they will or will not develop the disease. The context is therefore similar to CVD risk communication. This conceptualization of empowerment (but not the specific items of the instrument) therefore may also be a relevant framework for CVD risk communication. Using empowerment as a PRO corresponds with the overall goal of risk communication, besides increasing or preserving health, to enable informed choice and to empower individuals to gain control over the aspects affecting their health.

The above representation of empowerment is somewhat narrowly defined based on personal control and internal changes in an individual and not observable clinical improvements. There has been critique against defining empowerment in terms of control, since it could in fact be a sign that the individual is in denial of his/her actual risk and the consequences it has on their life. This can influence the individual to avoid taking actions to improve his/her health in the long-term [130], and might thereby reinforce the underestimation of CV risk, which is common within the public. Therefore, it might be positive to consider dimensions focusing on activation and self-management to ensure that individuals take certain actions in line with the core meaning of empowerment. However, a patient reported outcome should reflect the individuals' subjective perspective; therefore, one should be cautious about adding dimensions to better fit experts' theoretical view of what is empowerment. If the individuals' view of what is important does not fit the theoretical understanding of empowerment, then rather than to change the outcomes to better fit the concept of empowerment, it might be better to just give the concept another name.

Health literacy relates to the capacity to navigate and make use of the healthcare system and to search and use health information, which enables the individual to make informed health-related decisions [131]. Empowerment without health literacy can lead to choices that are actually detrimental to one's health, that is, choices that are not considered informed since they are based on incorrect information [132]. Therefore, improvements of health literacy may also be appropriate to add as a PRO for CVD risk communication, which has previously been suggested as a minimum outcome for health education interventions [131].

When considering outcomes for CVD risk communication, it is important to have reasonable expectations on what the risk communication can achieve. It may be unrealistic to expect that risk information, by itself, will influence

lifestyle, because of the structural and social factors that influence health be-havior [68]. Ideally, the risk communication is integrated in a wider process including activities such as lifestyle interventions and medical treatment, which can actually influence the physical health for those who need and desire to engage in that.

Methodological considerations

Focus group interviews were chosen for study I because they make use of the interaction between participants, and can be particularly helpful when discussing new subjects. Listening to other participants' statements can help partici-pants verbalize their own emotions and opinions [133]. One criticism of focus group interviews is that participants may feel inhibited about sharing their emotions, and dominant individuals might influence the group [83]. However, in this study, the participants asked questions directly to each other, made jokes, laughed and openly disagreed with each other, indicating an open dis-cussion climate.

Trustworthiness is a quality criterion for qualitative studies. To achieve trustworthiness, it is important to consider credibility, dependability, confirm-ability, and transferability [134]. Credibility refers to the confidence that the data and the interpretation of data is true. To achieve this, an observer partic-ipated in the interviews. At the end of the sections, we presented a summarized interpretation of the discussions to the participants, giving them an oppor-tunity to elaborate and comment on what they said. Two researchers were also involved in the data analysis. Dependability refers to data stability over time and conditions. This was achieved by conducting the interviews in the same way using the same interview guide. Confirmability refers to the objectivity and neutrality of the data. This was achieved by conducting a systematic anal-ysis where several researchers were involved. They first analyzed the tran-scripts separately and then compared and discussed the coherence of their findings. Examples of the analysis process and quotes from the participants were included when presenting the study in the final paper. Transferability refers to the generalizability of the data. Descriptions of the participants and the setting make it possible for the reader to evaluate the transferability of the results.

All participants in studies I, II, and III were SCAPIS participants recruited through the SCAPIS test center in Uppsala, Sweden. The SCAPIS participants were randomly selected from Uppsala Municipality. An analysis from the SCAPIS pilot study in Gothenburg, Sweden showed an overall participation rate of 50%, albeit a higher participation rate in higher socioeconomic areas (68%) compared to lower socioeconomic areas (39%). Participation was pre-dicted by being born in Sweden, cohabitation, university degree, and being employed [135]. This was also reflected in the sample in studies II and III,

which had a smaller proportion of people born outside of Sweden. This may have implications for the transferability of study I and the external validity of studies II and III. However, the sample was representative of Uppsala Municipality when it comes to educational level in this age span, except for a slightly smaller percentage of individuals who had only finished primary school [136]. Previous studies have found younger age, smoking [137], having low income, and living alone [138] as being associated with non-participation in general health checkups offered by the healthcare services. This might reflect that those accepting participation in SCAPIS might be the same people who would have accepted participation in general health checks as well, which strengthens the generalizability of the results to other health checkup contexts.

A random sample of the Swedish population was used in study IV to ensure a variety of experiences of different health examinations, as well as a variety of socioeconomic factors that can influence individuals' preferences. However, the response rate was only 29.9%. This may indicate a selection bias and puts constrains on the external validity by making it difficult to generalize the results to the general population since some groups in the society might not have been reached by this study. Six individuals contacted the first author (ÅG), declining participation because of language difficulties or because they found the survey too exhausting. Additionally, ten individuals informed us that they were lacking internet access and asked for a paper version of the survey. It is possible that more individuals did not participate due to limited internet access. Compared to the Swedish population, the respondents in study IV had a slightly lower proportion of people living alone, being born outside of Sweden, and only having primary school education, while the proportion of people with a university level was higher. Therefore, it appears that the results apply for the majority of the population, but the fact that the preferences of minority groups probably were not adequately captured by this study is acknowledged. It is likely that these groups would have preferred to receive their results via a letter since they lacked internet access. Due to a lower income and low health literacy in vulnerable groups [139], preferences for low costs, longer consultation time, and more expensive written test results would have been expected. Since low income has been associated with non-participation [138], it is also likely that a higher proportion of respondents would have selected opt-out.

In study II, the impact of risk information on HRQL and mental distress was investigated. A limitation of this study was the lack of a control group. The current design only allowed for the analyses of the differences among individuals who were referred to the hospital, to a PHCC, or who were not referred at all without any comparison with the general population. It is possible that participation in SCAPIS itself caused distress; however, this was not investigated in this study. There was only one follow-up measurement three

months after the participants' first visits. With an additional number of measurement time-points, it would have been possible to know the extent to which the increased distress was transitory.

Content validity refers to an instrument's ability to both cover relevant aspects of the construct being measured and exclude issues that are irrelevant [140]. Generic instruments such as HADS and SF-12, which were used in study II, have been criticized for providing a low content validity in screening contexts since they do not capture central aspects specific to the screened condition, e.g., anxiety about experiencing a myocardial infarction during physical activity for people with screening-detected stenosis. However, we did include a question about disease specific worry in experiencing a myocardial infarction, where a change was observed, which strengthens the results of the study. Furthermore, aspects not important for the specific context can contaminate the results [141, 142]. The items concerning physical health in SF-12 may have contaminated the results when measuring the impact of CVD risk communication, since it appears unlikely that CVD risk information could have a direct effect on the individual's physical health, in terms of pain, vitality, or fatigue.

In study III, the association between general health and family history on underestimating of CVD risk was investigated. The study uses cross-sectional data, which entails limitations regarding the causal path of risk perception. The fact that the majority of the study population was highly educated and born in Sweden also puts restraints on the generalizability, although not necessarily on the internal validity of the findings [143]. However, the study adjusted for education and other potential confounders, which is a strength of the study.

SCORE is a risk chart designed as a didactic tool for clinical practice, in situations where physicians have the possibility to take other risk factors into account, which was not possible in this study. The actual risk level, therefore, might not have been captured properly, implying that the participants' cardiovascular risks were estimated as lower compared to in clinical practice, leading to an underestimation of the association. In populations with a decreasing mortality rate, these risk estimates will automatically overestimate the risk level, as they are based on data from cohorts from the past. However, the Swedish 2015 SCORE version was recently validated for the Swedish population [88]; however, despite its flaws, it still appears to be the best available option to use in this study. The distribution of SCORE in our study sample is similar to that in the population-based MONICA study [88].

In study III, respondents' self-perceived risk was assessed using a relative measure of risk perception that includes sex and age. It was chosen to fit the sex- and age-dependent calculated SCORE risk and has also been used in previous studies [144, 145]. The methods used to measure risk perception in previous studies have varied, both regarding relative or absolute risk; moreover, the time frames and wordings differ. However, the tendency to underestimate

the CVD risk has been found regardless of the measurement, except for when the risk is assessed in percentages. Then, the CVD risk was instead overestimated [111].

The choice of attributes in a DCE is essential for the validity of study IV. There was a rigorous pre-work to select the attributes used in the DCE of study IV. This consisted of several steps, where both qualitative and quantitative procedures were used to ensure that the right attributes were chosen. The survey was also tested via think aloud interviews and pilot tested. This helped to strengthen the validity of study IV. The "hypothetical bias" may also affect the external validity of DCEs since the respondents are presented hypothetical choices, which may differ from their real-life choices. However, the results from a DCE in a recent study could to predict 91% real-world choices to opt for influenza vaccination at an individual level, which shows that stated preferences have the ability to predict real life choices [146]. The predicted uptake for the realistic scenario was on average 66%, which is similar to the observed uptake of 65% for a Swedish health checkup program [138], which further strengthens validity of the findings of the study.

Conclusions and implications

The participants largely relied on their general health and family history when assessing their own cardiovascular risk, which can lead to an optimistic bias. Health examinations, therefore, are crucial for helping to add a nuance to individuals' risk perceptions.

The test results were presented in medical terms and lacked recommendations for further action, making it difficult for lay people to understand and use, and sometimes also caused unnecessary worry. Therefore, there is a need for improvements regarding how personal risk information from health examinations is presented and communicated, both in research projects and in regular health services. In order for the public to obtain better cognitive and behavioral control, improvements should include presentation and assessment of written test results.

Most of the research participants were not emotionally affected by the cardiovascular risk assessment. However, there was an increase in mental distress among participants diagnosed with coronary artery stenosis. Thus, examinations should also include psychological support when needed in order to prevent unnecessary worry.

Cost was most important when deciding whether to participate in a health checkup. In addition to cost, how the results are communicated is crucial to achieve an uptake rate of > 70% recommended by the WHO. To optimize the use of health checkup test results especially for low health literate people, health checkups could be accompanied by consultations, tailored written reports, and lifestyle recommendations.

A PRO measurement is needed to capture the recipients' perspective of the benefits, and harms of CV risk communication, adequately. Empowerment may fit well, both as a theoretical framework when designing risk information and as an outcome when evaluating the impact of the risk information.

People with lower health literacy express a greater need for support to utilize their test results. Furthermore, increasing the health literacy of these individuals could be a reasonable goal and outcome for CVD risk communication. Meanwhile, health care professionals should recognize that an underestimation of CVD risk seems to be universal and cannot be explained by education or health literacy. Therefore, they should emphasize that CVD risk is multifactorial and development of CVDs is silent and symptom free when they communicate CVD risk to patients.

Further research

Vulnerable social groups are exposed to higher CVD risk. The fact that the majority of the respondents were highly educated and born in Sweden puts restrains on the analyses of vulnerability factors such as ethnicity. Future studies should aim to investigate the risk perception, preferences, and the impact of CVD risk communication in these groups, e.g., non-native speakers, people without internet access or digital competence, or groups that do not attend health checkups or seek care.

PROs are assessed at an individual level. However, to ensure that the information does not only benefit already privileged social groups in society, the impact of CV risk communication also needs to be evaluated at an aggregated level where comparisons can be made between the groups. This perspective is especially important for cardiovascular diseases since the mortality rate for CVD differs to a high degree due to demographic and socioeconomic factors.

In real life, people are exposed to thousands of different risks in their daily lives, not only connected to their health. In this thesis, CVD risk was not put in relation to other competing risks or life priorities. Therefore, even if the individual perceives his/her CVD risk as high, it is not possible to know whether there are other competing risks that are perceived as an even greater threat and therefore more prioritized.

The health checkups in the DCE study were traditional examinations that have been used for a long time. Future studies could investigate the preferences for health checkups that include new technology similar to the examinations used in SCAPIS to get an idea about the public's attitude toward these.

To evaluate the benefit of CVD risk communication from the recipients' perspective, adequate measurements are needed. Empowerment could be used as a framework to construct such instruments. Future studies should aim to construct and validate such an instrument.

Svensk sammanfattning

Hjärt-och kärlsjukdomar är den vanligaste dödsorsaken både i Sverige och i världen [3, 4] och påverkas i stor utsträckning av levnadsvanor som t.ex. rökning, fysisk aktivitet, matvanor och stress, men även ärftlighet spelar en roll för utvecklingen av hjärt-kärlsjukdomar [5]. Levnadsvanor är i sin tur starkt kopplade till social position, d.v.s. en individs utbildning, yrke, födelseland och inkomst, vilket bidrar till att hjärtkärlsjukdomar är socioekonomiskt betingade [8-10]. Många människor underskattar sin hjärtkärlrisk [48], vilket kan utgöra ett hinder för det förebyggande arbetet. Risk ett komplext begrepp och en persons riskupfattning påverkas av omedvetna processer kopplade till känslor och erfarenheter, så kallad heuristik [42, 45].

Utvecklingen av hjärt-kärlsjukdomar pågår under en lång tid och riskfaktorer som högt blodtryck och högt kolesterol är ofta symtomfria tillstånd som är svåra att upptäcka utan kliniska undersökningar. Hälsoundersökningar är en strategi för att identifiera påverkbara riskfaktorer hos den symtomfria befolkningen med syfte att förebygga hjärtkärlsjukdomar [16]. Riskinformation från dessa hälsoundersökningar kan vara till nytta för individen om den leder till informerade val, minskar individens sjukdomsrisk och förbättrar befolkningens hälsa. Riskinformationen kan också orsaka oro för något som faktiskt aldrig inträffar, eftersom inte alla personer med ökad risk kommer att utveckla hjärtkärlsjukdom. Dessutom har studier visat att allmänheten upplever svårigheter med att förstå innebörden av kardiovaskulär riskinformation som kommuniceras från exempelvis hälsoundersökningar. Riskinformation är betydelselös om målgruppen inte kan dra nytta av den. Därför är det avgörande att riskkommunikation optimeras. För att kunna göra det är det i sin tur avgörande att målgruppens perspektiv tas i beaktande och att man anpassar sig till hur målgruppen uppfattar risk, hur personlig hälsoinformation påverkar dem och vilka preferenser de har när det gäller riskinformation.

Det övergripande syftet med den här avhandlingen var att undersöka allmänhetens perspektiv av kardiovaskulär riskinformation, med fokus på hur de uppfattar sin risk, vad som påverkar underskattning av risk, hur kardiovaskulär riskkommunikation påverkar individers psykosociala hälsa samt deras preferenser för riskkommunikation.

Genom fokusgruppsintervjuer undersöktes i studie I forskningsdeltagares (n=31) uppfattningar och erfarenheter av att få tillbaka kardiovaskulär riskinformation från en omfattande hälsoundersökning. I undersökningarna ingick

bl.a. ultraljud och skiktröntgen för att undersöka åderförkalkning i halspulsåder och i hjärtats kranskärl. Resultatet visade att deltagarna i stor utsträckning förlitade sig på sitt allmänna hälsotillstånd och kroppsliga symptom när de bedömde sin egen risk för hjärtkärlsjukdom. Det fanns en benägenhet att förenkla orsakssambanden och deltagarna talade i termer av antingen/eller, och tillskrev hjärtinfarkter enskilda orsaker. Något som verkade spela stor roll för deltagarnas upplevda risk för hjärtkärlsjukdom var ärftlighet.

Deltagarna uttryckte en otillfredsställelse kring testresultaten eftersom de upplevde svårigheter med att förstå innebörden av resultaten och dess implikationer. De hade önskat att testresultaten hade sammanvägts till en helhetsbedömning av deras hälsa, och inte presenterats var för sig, för att göra det lättare att förstå. De saknade också vägledning kring åtgärder för att minska sin hjärtkärlrisk. För vissa deltagare väckte testsvaren oro, t.ex. testsvar gällande åderförkalkningar eller förhöjda kolesterolvärden, men deltagarna utryckte även tacksamhet över att få möjlighet till behandling och kände sig trygga i sjukvårdens omsorg. Deltagare med "normala" värden upplevde svaren som en lättnad och en bekräftelse på att deras livsstil var "bra" och att det inte fanns något behov av förbättring, något som kan utgöra en "falsk försäkran".

I studie II undersöktes om kardiovaskulär riskinformation påverkade oro för framtida hjärtinfarkt, ångest, depression och hälsorelaterad livskvalitet. Det mättes genom en enkät som deltagarna besvarade innan och efter att de fått sina testsvar. Studiepopulationen bestod av forskningsdeltagare från SCAPIS Uppsala (n=435), män och kvinnor i åldrarna 50-64 år. Resultaten kunde inte påvisa några skillnader varken för deltagare som fått "normala testsvar" (ingen hänvisning vidare till vårdcentral eller sjukhus) eller för deltagare som hänvisats till vårdcentral. Däremot observerades en ökad nivå av oro för hjärtinfarkt och en ökad nivå av ångest för deltagare som hänvisades till sjukhus. Vidare observerades ett statistisk signifikant samband mellan ökad oro och ångest och att ha diagnostiserats med kranskärlsstenos.

Studie III var en tvärsnittsstudie som undersökte sambandet mellan I) självskattad hälsa och II) familjehistorisk av hjärtinfarkt och underskattning av sin kardiovaskulära risk (beräknad utifrån SCORE). Den analysen valdes utifrån resultat från studie I. Deltagarna (n=384) var forskningsdeltagare från SCAPIS och bestod huvudsakligen av högutbildade personer födda i Sverige. Resultatet visade att personer med en mycket god eller utmärkt självskattad hälsa var mer benägna att underskatta sin kardiovaskulära risk jämfört med personer med dålig eller ganska god självskattad hälsa (justerad oddskvot 2.60, 95% konfidensintervall 1.10-6.16). Personer utan familjehistoria av hjärtinfarkt var mer benägna att underskatta sin kardiovaskulära risk jämfört med deltagare utan familjehistoria av hjärtinfarkt (justerad oddskvot 2.27, 95% konfidensintervall 1.24 -4.18).

Studie IV var en tvärsnittsstudie som undersökte allmänhetens preferenser för hur testresultat från hälsoundersökningar ska kommuniceras. I studien användes en webbaserad enkät som innehöll en s.k. DCE (Discrete Choice Experiment), vilket innebär att deltagarna ställs inför upprepade, hypotetiska valsituationer där de ombeds att välja mellan två olika hälsoundersökningar. Hälsoundersökningarnas kostnad och hur testresultaten skulle kommuniceras skiljde sig åt. Resultatet visade att deltagarnas val av hälsoundersökningar framförallt påverkades av kostnaden för hälsoundersökningen, följt av rådgivning av medicinskt kunnig person, huruvida livsstilsrekommendationer inkluderades, omfattning av det skriftliga resultatet, väntetid på resultaten och hur resultaten meddelades (bara via elektronisk journal eller via elektronisk journal och brev). Studien fann skillnader i deltagarnas preferenser som visade sig i tre olika grupper av preferensmönster. Två av grupperna var positiva till att delta i hälsoundersökningarna medan den tredje mindre gruppen var negativ. Deltagare med låg hälsokompetens hade större sannolikhet att dels tillhöra gruppen som värdesatte konsultationstid och mer omfattande skriftliga testresultat mest, och dels gruppen som var negativ till deltagande och som värdesatte låga kostnader och att även få svaren hemskickade via brev. Det förväntade deltagandet beräknades för olika hälsoundersökningar baserat på hur kostnaden och hur resultaten kommunicerades. Den beräknade deltagarfrekvensen varierade mellan 7 % - 88 % mellan det minst och mest eftertraktade hälsoundersökningsscenariot och stora skillnader mellan grupperna observerades. Gruppen som var negativa till att delta i hälsoundersökningarna nådde som högst ett förväntat deltagande på 20 % fastän hälsoundersökningarna gjordes helt kostnadsfria.

Studiernas slutsatser var bland annat att deltagarna förlitade sig till stor del på sin självskattade hälsa och familjehistoria när de bedömde sin egen kardiovaskulära risk, vilket kan leda till att risken underskattas. Hälsoundersökningar är därför viktiga för att nyansera individers riskuppfattning och uppmärksamma påverkbara riskfaktorer.

Testresultat som skrivs i medicinska termer och som saknar rekommendationer för vidare handling gör det svårt för lekmän att förstå och nyttja riskinformation. Det finns därför ett behov av förbättringar av hur personlig riskinformation från hälsoundersökningar presenteras och kommuniceras, både i forskningsprojekt och i den ordinarie hälso- och sjukvården. Det bör också tas i beaktande att vissa typer av testsvar, t.ex. rörande kranskärlsstenoser, kan ge upphov till oro. Därför är det viktigt att det finns en beredskap för att fånga upp dessa individer och erbjuda dem stöd.

Kostnaden var viktigast när man beslutade om man skulle delta i en hälsoundersökning. Förutom kostnad är det avgörande hur resultaten kommuniceras för att uppnå en deltagarfrekvens > 70% vilket rekommenderas av WHO. För att se till att resultatet från hälsoundersökningar kommer till nytta på bästa sätt, särskilt för personer med låg hälsokompetens, bör rådgivning, anpassade skriftliga testsvar och livsstilsrekommendationer inkluderas. Hälsokompetens

är viktigt att ta hänsyn till när hjärtkärlrisker kommuniceras. Personer med lägre hälsokompetens uttrycker större behov av stöd för att använda sina test-resultat. Att öka hälsokompetensen hos dessa individer kan dessutom vara ett rimligt mål för kommunikation av risk för hjärtkärlsjukdom.

Acknowledgements

First and foremost, I am grateful to the respondents who answered the questionnaires used in my studies and the participants that openly shared their experiences in the focus group interviews. Thank you for your time and effort. Your contribution constitutes the core of this thesis.

This thesis would not have been possible without the financial support from the Swedish Heart and Lung Association.

I am grateful to *Emma Larsson* and *Anna Frick* (SCAPIS), who helped me with data collection and data access. Furthermore, I would like to thank *Maria Storgärds, Emil Hagström,* and the rest of the workforce at the SCAPIS test center in Uppsala who provided me with valuable information and helped me with the recruitment of participants for the focus group study.

I am thankful for the guidance and support I received from my supervisors and co-authors during my doctoral studies. I am truly honored and thankful to have had the opportunity to work with such merited and competent researchers. You are true role models, representing a positive culture within academia by always being kind, humble, supportive, and generous.

I am especially grateful to my main supervisor, *Mats Hansson*, for giving me this opportunity. I could not have wished for a better supervisor. You have encouraged me, believed in me, supported my decisions and wishes, and promoted me in all kinds of different situations. It has been so much fun working with you; thank you!

Thank you *Jorien Veldwijk*, my co-supervisor, for your devoted support and guidance. I really appreciate your patience and the hours you spent teaching me about DCE and statistical analysis. Thank you also for welcoming me into your home in the Netherlands.

Thank you *Stefan James*, my co-supervisor, I am enormously grateful and honored to have had such clinical expertise onboard. Thank you for always being available and providing me with clear and valuable input, and for your remarkable kindness.

Thank you *Anna Höglund*, co-author in study I. I appreciated our rewarding collaboration in the qualitative study. Thank you for your straightforward guidance and encouragement.

Thank you *Liisa Byberg,* co-author in study III. I am truly grateful for everything you taught me about epidemiology during our collaboration in paper III. Thank you for your time, patience, and guidance. You are a great educator.

Thank you *Brett Hauber,* co-author in study IV. It has been a great honor to collaborate with you in my DCE study. Thank you for all your input. It has been most valuable and taught me a lot.

A special thanks to *Jennifer Viberg Johansson*, who has been my informal supervisor from day one, by supporting and helping me out with just about everything. I appreciate your time and effort, and I am grateful for our uplifting talks and friendship.

Thanks to all my colleagues at CRB for providing me with an inspiring research environment. Our engaging seminars have been most helpful. I also appreciate the fun times we have had together; the sing-along at Krusenberg was great fun! A special thanks to *Josepine Fernow* and *Anna Holm*, for turning my research into lay language news, designing posters, and creating a very nice invitation letter for my final study. Your communication skills constantly impress me.

I appreciate all the support I received from the administration; thank you *Henrik Edlund* and *Renée Sundbom* for being most helpful.

Thank you *Erik Berglund* and *Jessica Nihlén Fahlquist* for giving me opportunities to teach public health classes during my Ph.D. studies.

I am grateful for my present and former doctoral colleagues at the Department of Public Health and Caring Sciences. Thank you, *Mona Pettersson, Helena Tegler, Jennifer Drevin, Elisabet Fält, Sofie Vengberg, Camilla Nystrand, Linn Kullberg, Anton Dahlberg, Richard Ssegonja, Lisa Hultin, Amal Matar, and Kajsa Norbäck.* A special thanks to *Karin Schölin-Bywall* and *Mirko Ancillotti*. It has been a pleasure conducting our doctoral studies in parallel. Thanks for the support and for being great travel companions when going to Basel, Leiden, and Manchester. *Karin*, I will never forget my first day at work when we were at Arlanda Airport leaving for Basel, and definitely not the emergency landing on our trip home.

Thank you *Monica Cornefjord*, for your great leadership, encouragement and for believing in me. It made an impact.

To my friends and family who helped me with my studies by sharing your thoughts and experiences, testing and distributing surveys in your networks, and providing me with most valuable input. Thank you for your time and effort.

I am grateful to be a part of a great community that has brought me a lot of love and joy during these four years.

Thanks to my amazing friends, *Lotta, Frida*, and *Daniel*. I am very grateful of our friendship. Thanks to my book club friends, *Karolina, Mona, Lina, Maria, Marie, Eva, and Jennifer*. You are all such amazing women. Thanks *Karolina* for initiating the book club and for the opportunity to do my bachelor's thesis at the primary health care unit many, many years ago. Thanks to my "Art friends," *Victoria, Lisa, Helena,* and *Emma*. I always laugh when I am with you. Thanks to my unbelievable neighbors (and former ones), *Hannes, Elin L, Lisa B, Johannes, Jenny, Staffan, Elin R, Patrik, Björn, Lisa N*, *Maria,* and *Martin* for the parties, forest hikes, travels, and workouts. I am definitely in better shape since I met you!

A special thanks to *Eva*; what would I ever do without you? Thanks for your honesty, humor, and warmth. I am grateful for all the things we share. Thanks also to *John-John, Edward, and Lillian* for all the wonderful moments we have shared, like driving around in Italy and relaxing in Frascole. You are very dear to me.

I am grateful for my brothers, sisters- and brothers-in-law and all the kids, *Jocke, Erika, Loke, Moa, Jonny, Mikaela, Daniella, Alicia, Kajsa H, Simon, Cesar, Isolde, Samuel, Jessica, Carmen, Hampus,* and *Mia H*.

Thanks to my mother-in-law *Mia* and *Peppe,* for the love, support and your great hospitality. Thanks to my father-in-law Baruch, for being generous and for supporting Joel when times were tough. I am grateful for all other relatives and friends who have provided me and my family with good times and nice traditions. A special thanks to *Jörgen*, *Kajsa A, Mathilda, Peter A*, *Jonas* and *Therese*. You mean a lot to us.

Thank you, *Mom*, for always allowing me to be me and encouraging me to trust my gut feeling. Thank you also for introducing art and theater into my life. Thanks *Dad*, for being reliable and humble and for your great generosity. Thank you also for your humor, playfulness, and for introducing sports into my life. Forza Sirius!

Finally, I would like to express my deepest gratitude to my family. *Anton* and *Ines*, words cannot describe how proud I am of being your Mom. You bring joy and meaning to my life each and every day. *Joel*, this would not have been possible without you. Thanks for your enormous support and for always believing in me. You made it easy to combine my doctoral studies with family life (except for bringing a puppy into our life at the end of my doctoral studies, I don't know what you were thinking). Jag älskar er. Alltid. Oavsett.

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Appendix 1: Interview guide used in Study I

Interview guide, Study I

Theme		Question and probes
		General probes throughout the discussion:
		Do the rest of you recognize yourself in previous statement?
		Was it the same for the rest of you?
		Could you tell us more about that?
Opening question		
(Round the table. All answer)	1	Could you please tell us about why you choose to participate I SCAPIS?
		Thank you, from now there is no need to take turn when answering. Feel free to speak freely.
Introductory question		
Expectations	2	You underwent a number of tests. Could you tell me about your expectations on the result? *Probe: where there something that you were specifically interested in finding out?*
Transition question		
Waiting for the test result	*3*	How was it to wait for the test result?
Key questions		
		When you finished all of the examinations, all participants received a rapport via e-mail and additional information could be accessed through you electronic medical record. Some participants were also referred for further investigation.
Result: Perceptions and attitude	*4*	What are your thought about the information you received? *Probe: Did you miss something?*

Result: Understanding and presentation	5	What do you think about the way the result was presented? *Probe: Would you have wanted it in some other way?* What are your thoughts regarding understanding the information? *Probe: Did you do something to better understand the result?*
Result: Feelings	6	What kind of feelings or thought did the result evoke?
Influence of test result: View on health status	7	In what way, would you say the test result influenced how you view your own health? *Probe: have it in any way affected how you view your own future?*
Influence of test result: on daily life	8	Have the test result in any way influenced your daily life, and your wellbeing?
Influence of test result: acting on the result	9	Did any one made any active changes due to what you found out in the study?
Ending		
Summary and assurance	10	Summary of the discussion. Was that a fair description of what we talked about? Is there something you would like to clarify or add? If the something we forgot to talk about? Ask the observer for further questions or reflections.
		Thank you for participating!

Appendix 2: Attributes and levels in study IV

Attributes	Levels
Written results: How your test results are presented to you in a written format.	**Numerical test results** with reference values of what is considered normal for the population
	Numerical test results and Everyday words. Besides numerical values, your test result is also presented in everyday words
	Numerical test results, Everyday words and Overall assessment. Besides numerical values and everyday words, your test result include an overall assessment where all test results are included, as well as life style factors and individual factors such as age and sex.
Notification method: Your test results are documented in your medical health record. You can access your test results by logging in to your electronic health record online.	**Only electronic health record.** You will receive your written test result only by personally logging in to your electronic health record.
	Electronic health record + letter. Besides having access to your written test results through your electronic, you will also receive a letter to your home address or e-mail.
Waiting time: How long you will have to wait for your written test results.	**2 days**
	1 week
	2 weeks
	3 weeks
Life style recommendations: There are actions you can take yourself to influence your cardiovascular risk, thing related to your life style.	**No,** life style recommendations are not included
	Yes, life style recommendations are included

Consultation time: Time with a medically trained person with high competence within the area, to get the opportunity to discuss and ask questions regarding your test results.	**No consultation time.** You will only receive written results.
	15 minutes. Face-to-face or over the phone
	30 minutes. Face-to-face or over the phone
Cost*: What you pay out of your own pocket	**Free of charge**
	€ 15 (150 SEK)
	€ 30 (300 SEK)
	€ 60 (600 SEK)
	€ 90 (900 SEK)
	€ 120 (1200 SEK)

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