Summary

With the rapid developments in the field of health screening technology, people are increasingly confronted with new information about their susceptibility to a range of diseases. This information includes genetic risk information based on DNA testing or family disease history and information on other risk factors such as advanced age, raised cholesterol levels, high blood pressure, (central) obesity and being a smoker. Whether or not people benefit from these developments may not only depend on the changeability of risks, i.e. risk reducing options, but also on how people think of the risk and perceive themselves in relation to these risks ("The Risky Self"). People will try to make sense of their at-risk status by integrating new information concerning their health into a mental model that already exists in their minds. This model includes beliefs about the magnitude, nature, sources and controllability of the risk. The process of integrating risk information is influenced by people’s ideas about who they are as a person, i.e. the self-concept. People’s mental model of being at risk will also guide the identification and potential use of appropriate means to reduce risk. That is, people may only adhere to preventive recommendations if the recommendation corresponds with their representations of risk.

The central objective of the study project was to gain understanding on how people perceive and respond to being at risk for two common chronic diseases: type 2 diabetes (T2D) and cardiovascular disease (CVD). In this thesis the following questions are addressed:

1. How do people perceive being at risk for diabetes and CVD?
2. How is the awareness of different types of risk factors, in particular genetic versus other risk factors, and people’s self-concept related to mental models of being at risk for diabetes and CVD and to preventive behaviour?

Data were collected from three separate samples at risk for diabetes and/or CVD: individuals recently diagnosed with Familial Hypercholesterolemia (FH) based on DNA testing (sample 1; n = 81), individuals recruited among patients (registered with general practices) with a suspected high risk for CVD, participating in an ongoing intervention study aimed at improving patient adherence to lifestyle advice (sample 2; n = 49), and individuals who had taken part in a population based screening program to identify people with undiagnosed T2D, five years earlier. All participants were identified as at risk during the screening, based on family history and other risk factors, but did not have T2D at the time of testing, nor at recruitment in the present study project.

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1 As most lay persons do not distinguish between different forms of diabetes we use the generic term diabetes when referring to people’s illness beliefs.
Chapter 2 describes a study that examined self-reported risk factors, causal beliefs and perceptions of diabetes and CVD risk in at-risk individuals (sample 3). In this study, participants demonstrated better knowledge about the causes of CVD risk than about the causes of diabetes risk. Although family disease history was associated with higher perceptions of diabetes and CVD risk, in general, self-reported risk factors were only partially translated into perceptions of risk. In particular, being overweight and smoking was not associated with higher perceived disease risk of diabetes and CVD, respectively. However, being overweight and believing that overweight could be a cause of diabetes was associated with higher perceptions of diabetes risk. Similarly, believing that smoking could be a cause of CVD and being a smoker was associated with higher perceptions of CVD risk.

Chapter 3 describes the mental model of being at risk for CVD and preventive behaviour of individuals diagnosed with FH (sample 1). In general, participants in this study seemed to underestimate their risk of developing CVD. Although participants almost equally endorsed both genetic and lifestyle attributions of CVD, they viewed the adoption of a healthy lifestyle as somewhat less effective than medication in reducing risk of CVD. Moreover, while they reported almost optimal adherence to medication they did not always show adequate adherence to lifestyle recommendations. Participants with a stronger family history, i.e. a higher number of 1st degree relatives affected by CVD, perceived a higher risk and were more likely to adhere to lifestyle recommendations.

Chapter 4 describes a cross-sectional study that compared and examined differences in the mental model of being at risk for CVD and preventive behaviours of at risk individuals with (sample 1) and without an established genetic predisposition to CVD (sample 2). Risk perceptions, genetic attributions of CVD and efficacy of medication were higher in the sample with an established genetic predisposition than in the sample without an established genetic predisposition. However, these differences were best explained by individual differences in the number of first-degree relatives that had CVD and not by sample per se (i.e. positive DNA test result). The samples did not differ on lifestyle attributions, efficacy of a healthy lifestyle, or preventive behaviour.

Chapter 5 reports the results of an analogue study testing the hypothesis that fatalistic responses to risk information, i.e. the belief that little can be done to change risk, is a function of type of risk information and differences in self-concept (Self-Malleability). In particular, DNA-based risk information was assumed to generate more fatalism than risk information based on family history or non-genetic risk information only. Moreover, people who view themselves as more rather than less
able to change, were hypothesized to respond least fatalistically. Participants responded to three scenario vignettes in which they were informed about an increased risk of CVD: ascertained by DNA-testing, family history and cholesterol testing, by family history and cholesterol testing, and by cholesterol testing alone. The DNA-scenario triggered most fatalistic responses; it was associated with least perceived control over CVD-risk. People who viewed themselves as more able to change responded less fatalistically, they experienced more control in all three scenarios.

Chapter 6 describes the results of a study examining the potential impact of family history and Self-Malleability on control beliefs and preventive behaviour in individuals at risk for T2D (sample 3). The study employed a structural equation modelling approach to analyze all relationships between the constructs simultaneously. Family history was positively associated with the adoption of a healthy diet and sufficient exercise but was not associated with perceived control over diabetes risk or perceived efficacy of preventive behaviour. Higher Self-Malleability was associated with higher perceived control.

Chapter 7 discusses the evidence from other studies for the use of family history as a tool for primary prevention of common chronic diseases (i.e. T2D, CVD and several types of cancer), in particular for tailored interventions aimed at promoting healthy lifestyles. There is ample evidence that detailed family history information can be used - along personal risk factors such as weight and smoking status - as a simple, easily applied and cost-effective tool to determine a person’s disease risk. In addition to risk assessment, family history information may also be used to personalize health messages, which are potentially more effective in motivating people to adopt and maintain a healthy lifestyle than standardized health messages. A personalized health message should be phrased in such a way that it fits within the target’s pre-existing mental model of being at risk. In this way, personalized risk information could correct erroneous beliefs, fill knowledge gaps, and reinforce people’s confidence in their ability to reduce risk by changing behaviour. The evidence for the effectiveness of using family history information as a personalized tool for disease prevention, in particular for raising motivation to adopt and maintain a healthy lifestyle, is limited. More research is needed before a definite answer can be given to the question of whether and how family history information should be used and promoted as a tool to motivate people to change their behaviour.

In the final chapter of this thesis, the main findings are discussed. Overall, the study findings suggest that genetic risk information does not induce a sense of fatalism nor that it lowers people’s confidence in the efficacy of preventive options, in particular of adopting a healthy lifestyle. Moreover, having a positive family history of diabetes and/or CVD is likely to raise perceived
susceptibility to disease and increase motivation to engage in healthy lifestyles. There was no evidence for an effect of positive DNA information (confirming a genetic susceptibility) in addition to family history information. Besides family history, beliefs about disease causation have an impact on perceived susceptibility to diseases. Self-Malleability, a self-concept measure that assesses the extent to which people believe themselves as able to change self-attributes, plays a minor role in explaining perceptions of control. Although more research is needed our findings should be considered when developing tailored and personalized risk messages.