Summary
Introduction

Colorectal cancer (CRC) is one of the most common causes of cancer death in developed countries. Population-based CRC screening is widely recommended as it can reduce the incidence and mortality of CRC. CRC screening involves possible benefits, but there are also possible downsides, such as false positives, false negatives, overdiagnosis, overtreatment and risks associated with sigmoidoscopy/colonoscopy. Whether the possible benefits for an individual outweigh the possible downsides depends on how that individual perceives and values the possible benefits, harms and risks of CRC screening. Therefore, experts in the field of cancer screening increasingly consider it important that people make a personal and informed decision concerning CRC screening participation. However, appreciation of this notion is a relatively recent development, and for many decades, universally, the main communication about cancer screening in general consisted of conveying to the public that it was a good thing to do. Therefore, it is likely that among the public there is a preconceived notion that participating in cancer/CRC screening is something positive.

Many studies have been conducted on CRC screening participation. The main focus of previous research seems to have been to examine whether an informed decision has been made and which reasons and factors were associated with screening-uptake or participation. Although these previous studies provide useful insights into why people do or do not participate in CRC screening, it appears that research on particularly the process of decision-making, and factors affecting this, could be expanded on. Therefore, the main objective of this thesis was to gain more insight into the individual decision-making process regarding CRC screening as well as into the societal context (i.e. public opinion) within which this decision is being made. Subsequently, these insights could be used to further develop support to people when making their CRC screening decision and optimise their decision-making process. Specifically, we focused on examining the following main aspects: 1) Public opinion concerning the Dutch CRC screening programme and related public perceptions; 2) People’s focus and decision-making style regarding the CRC screening decision; and 3) The concepts of autonomous and informed decision-making in relation to decision-making in real life. Additionally (4), in a few of
the studies we conducted, we examined possible differences associated with people’s sex, age, education and/or health literacy.

Main findings

1) Public opinion concerning the Dutch CRC screening programme and related public perceptions

Our results showed that the Dutch public were in general positive about and supportive of the CRC screening programme, and that more people had heard about the possible benefits of CRC screening than about its possible harms and risks. Additionally, we found that the public’s positive attitude towards preventive health screening in general, their perceived seriousness of cancer, their belief that health was important, and their trust in the government regarding national screening programmes were all positively related to public opinion concerning CRC screening.

2) People’s focus and decision-making style regarding the CRC screening decision

People have specific goals they want to achieve when making health-related decisions. A well-known theory in researching people’s goals and their orientation or focus is the Regulatory Focus Theory. Guided by this theory, we distinguished between people having a promotion-orientation, where people want to achieve being healthy, and a prevention-orientation, where people want to avoid getting ill. Another related distinction that could be made is that between having a focus on mainly the advantages of CRC screening or the disadvantages when deciding about participating in it. Our findings indicated that CRC screening participation was related to a focus on the advantages of CRC screening and, within that, CRC screening participants had both a promotion-orientation and prevention-orientation. This means that CRC screening participants were focusing on achieving becoming healthy as well as avoiding getting ill. CRC screening non-participation, on the other hand, in our study, appears not to be related to a clear goal-orientation or focus. Regarding decision-making style, we differentiated between a rational, intuitive, dependent, avoidant and spontaneous style, as identified by Scott and Bruce (1995). We found that those deciding about CRC screening participation scored highest on using both a rational and intuitive decision-
making style. Although the differences are small, people scoring higher on using a spontaneous decision-making style were more likely to have participated in the CRC screening programme, while people scoring higher on using an avoidant decision-making style were more likely not to have participated in the CRC screening programme. In general, people experienced low decisional conflict, indicating they felt certain about their CRC screening decision and positive about its quality.

3) The concepts of autonomous and informed decision-making in relation to decision-making in real life

Our qualitative study showed that our sample of the eligible CRC screening population viewed aspects related to the concepts of autonomous and informed decision-making as being important for making a ‘good’ CRC screening decision. Most interviewees considered a ‘good’ CRC screening decision as one they stand by, based on both reasoning and feeling/intuition, and that is made freely. However, many CRC screening non-participants experienced a certain social pressure to participate. Additionally, the strong emphasis on making a fully informed and well-considered screening decision, as is the core of informed decision-making, does not appear to be entirely reflective of the CRC screening decision-making process in practice.

4) Differences associated with people’s sex, age, education and/or health literacy

Our findings showed that higher educated people were less supportive and positive about the CRC screening programme than lower educated people, while older people, compared to younger people, had a more positive attitude towards the CRC screening programme. Additionally, the higher educated answered more of our knowledge questions about CRC screening correctly. Among the eligible CRC screening population, we mainly found that higher educated people were more likely not to have participated in screening compared to lower educated people, and to have less of both a promotion- and prevention-orientation.
Discussion

The findings of this thesis indicate that the present, expert-defined, concept of informed decision-making, with its strong emphasis on making a fully informed and well-considered screening decision, does not correspond with how people make their CRC screening decision in real life. This is not an unexpected outcome as the Rational Decision model underlying the concept of informed decision-making has been challenged since the 1950s, and its practical limitations have been acknowledged. A common alternative view of decision-making is that of the adaptive decision-maker with bounded rationality. Rather than complete information use, the notion of adaptive decision-making proposes that decision-makers prioritise which information to focus on and adjust their decision-making strategy to the situation and task-demands at hand. People in our thesis expressed a need for information and used reasoning, but did not need to be fully informed, and factors such as intuition, experiences, existing views and life values were also important for making their decision. Although people are not necessarily making fully informed CRC screening decisions, solely based on reasoning, they still felt satisfied and certain about their CRC screening decision. That being said, the existence of a positive public opinion or social norm regarding cancer screening participation could be affecting an autonomous decision-making process, especially for those considering not participating in CRC screening. In addition, people value having basic knowledge about CRC screening in order to better understand the choice-options. In this light, concerns arise as to whether people’s individual CRC screening decision as well as the present positive public opinion are sufficiently informed, especially concerning the possible harms and risks of CRC screening. The findings of this thesis raise the question of whether the concept of informed decision-making, in its current strict form, is something we wish to pursue. Additionally, if we want to pursue a form of informed decision-making, it raises the question of how best to accomplish this.

Suggestions for future research

People’s positive view regarding cancer screening and preventive health screening in general, their view of cancer being a serious disease, and their focus on mainly the advantages of CRC screening, could impede them from appreciating the possible harms
and risks of CRC screening. Future research could focus on how best to design public communication and education materials to foster people becoming informed about relevant aspects concerning CRC screening. Knowledge of people’s existing perceptions and specific goals and values is useful in this context. Information about the harms and risks of CRC screening may be noted and incorporated better if in communication and education materials this is discussed within, and actively connected to, people’s ‘mental framework’ of existing goals and views. However, more knowledge concerning people’s specific goals and values in the context of CRC screening is needed. Additionally, future research recently initiated by Timmermans et al. will focus on developing and validating a new measure for informed decision-making in cancer screening. Other future research could focus on examining to what extent, and according to who’s standard (e.g. expert and/or target population), being informed should be pivotal in evaluating CRC/cancer screening decisions, as well as on examining possibilities other than informed decision-making to measure the quality of people’s decision.

Reflections and implications regarding public health policy and screening practice

People form their opinion and make their decision concerning CRC screening within a social context based on previous experiences, existing views and a broad set of values. This context can affect the process of making an autonomous and informed decision. It could be argued that a responsibility lies with those involved in CRC screening policy and practice to provide the conditions necessary for making an autonomous and informed decision. Therefore, they should be aware of existing norms and the existing diverse views, goals and values. Subsequently, as also mentioned in our ‘Suggestions for future research’ section, public communication should encourage people to make an informed screening decision by communicating relevant aspects of CRC screening in a manner that appeals to how people think and what they believe to be important. However, this is not an easy task as the public and eligible CRC screening population consist of different subgroups with different views. For these different subgroups, different types of communication materials might be necessary, as well as a layered structure of information provision. Tailoring information to the target population and the context in
which their decision is made, is already being done. Our thesis contributes to how this could be optimised. For those involved in CRC screening policy and practice, it is also relevant to consider, and make explicit, the purpose of providing support to people when making their CRC screening decision. For example, is the purpose that people make a decision they consider to be a good decision for themselves, or one that is considered informed according to expert standards? Different objectives could result in different approaches concerning public communication and decision-support. From a psychological perspective, the main purpose would be to support people in making a CRC screening decision that corresponds with their personal goals and values. This includes being informed, as both the target population and experts consider it important to have basic knowledge concerning CRC screening to better understand the choice-options.