CHAPTER 8

General Discussion and Conclusion
The main objective of this thesis was to gain more insight into both the individual decision-making process regarding CRC screening and the societal context 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. In this chapter, we will discuss our main findings in relation to scientific literature, public health policy and screening practice.

1. Main findings

Figure 1 shows the conceptual framework that we used in examining the decision-making process concerning CRC screening participation (derived from ZonMw/Timmermans (2013), ‘What moves the decision-maker?’). It follows the notion that aspects related to the choice problem at hand, individual characteristics and the environment all affect how people approach a choice or decision (1).
In this thesis, we specifically focused on examining the following four main aspects:

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 of health being 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 regarding a decision is the Regulatory Focus Theory (2). Guided by the synopsis of this theory, we distinguished between people having: 1) a promotion-orientation, where people want to achieve a positive end-state (e.g. being healthy), making them focused on desires and possible gains; and 2) a prevention-orientation, where people want to avoid a negative end-state (e.g. getting ill), making them focused on safety and potential losses (2, 3). Promotion-orientation and prevention-orientation are two distinct orientations that people can have towards a decision, but they are not each other’s opposites (2, 4, 5). Another related distinction that could be made is that between having a focus on mainly the advantages or the disadvantages of CRC screening when deciding about participating in it (2). 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 aimed at achieving being healthy as well as avoiding getting ill (2). On the other hand, CRC screening non-participation, in our study, appears not to be related to a clear goal-orientation or focus.

Regarding decision-making style, we differentiated between five general styles, as identified by Scott and Bruce (1995) (6): 1) a rational style, where the emphasis lies on a thorough and logical process; 2) an intuitive style, where the emphasis lies on the use of intuition and inner feelings; 3) a dependent style, where the emphasis lies on relying on the advice of others; 4) an avoidant style, where the emphasis lies on avoiding the actual decision-making; and 5) a spontaneous style, where the emphasis lies on making the decision as soon as possible and in the moment (6). These decision-making styles are independent, but not mutually exclusive (6, 7). In our study, we found that those deciding about CRC screening participation scored highest on using both a rational and intuitive decision-making style. Although differences were small and it concerns relatively small groups of people, 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 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 the present definition 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. Furthermore, the public were more aware of the CRC screening programme, and specific aspects of it, when female, older or higher educated. 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.
2. Discussion of the findings

Informed decision-making versus decision-making in real life

Population-based CRC screening is widely recommended (8-11) as it can reduce the incidence and mortality of CRC (12-15). However, in addition to these possible benefits, CRC screening involves possible downsides, such as false positives, false negatives, overdiagnosis, overtreatment and risks associated with sigmoidoscopy/colonoscopy (10, 11, 16-19). 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 (20-22). Therefore, experts in the field of cancer screening consider it important that people make a personal and informed decision concerning CRC screening participation (23, 24). The underlying framework for the concept of informed decision-making is the Rational Decision model (25, 26). This model assumes that people base their decision on making maximum use of information and rationally weighing all aspects involved. An informed screening decision is commonly defined as:

A deliberative decision based on sufficient and relevant knowledge concerning the different choice-options (i.e. fully informed) and consistent with the decision-maker’s values, often operationalised as their attitude towards screening and/or their preferences towards a screening test (23, 27, 28). A central part of an informed decision is also that it is one’s personal and free decision (i.e. autonomous decision).

In this thesis we found that, for the majority of our study sample, the decision concerning CRC screening involved both rational and intuitive processes and decision-making styles. Furthermore, although most respondents in our interview study indicated they wanted to have some notion of what the CRC screening programme entails and its purpose, many made their decision without being fully informed or making a deliberative weighing of all aspects involved. Additionally, most interviewees used experiences as an information source and found it essential that their decision was made only by themselves and freely, as well as ‘feeling right’. Moreover, values broader than people’s attitude or preferences (i.e. how decision-maker’s values are often
operationalised within the concept of informed decision-making), were involved in their decision-making, for example, life values regarding people’s health and quality of life. These findings 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, partly but not entirely corresponds with how people actually make their CRC screening decision. This is not unexpected, as similar results have been found regarding, for example, prenatal screening (29). Furthermore, the Rational Decision model underlying the concept of informed decision-making has been debated since the 1950s, and its practical limitations have been acknowledged (e.g. (30, 31)). A common alternative view of decision-making is that of the adaptive decision-maker with bounded rationality (32, 33), which has gained increased empirical support (34). 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 (35, 36).

The impact of public opinion and a social norm
As previously mentioned, we found public opinion to be positive concerning the CRC screening programme. This is not surprising as, for decades now, the prevailing message given to people was that cancer screening is a good thing to do and that they should participate in it (16, 24, 37, 38). Furthermore, in the Netherlands, as well as some other countries such as the United Kingdom (UK) or Australia (39, 40), CRC/cancer screening is organised by the government, with people being actively invited to participate in it, which can give people the impression that participating is a good thing to do (41-43). Since the beginning of the 21st century, experts in the field of cancer screening have turned their attention more on enabling people to make a personal and informed screening decision and, therefore, providing them with complete and balanced information (20, 23, 44). This development is related both to the idea that people will make healthier life decisions if they have more knowledge about the scientific facts and relevant aspects involved (1) and with the societal shift of autonomous decision-making becoming more prominent (45, 46). Although the option of not participating in cancer screening has always existed, this option might not have been as apparent, or perceived as acceptable, as the option to participate. Especially since strategies such as sending
people a personal screening invitation with a changeable but given date, time and place have also been used (47-49). It is therefore plausible that it will take time for people to adjust to the different message that screening participation is their free and own decision, based on their personal situation and values as well as balanced information about both the possible benefits and downsides of cancer screening (20, 23, 44). However, the present positive public opinion or perceived social norm regarding cancer screening might be a concern as we found that it could result in a perceived social pressure to participate. This could affect people’s freedom of choice and the degree to which they feel free to decide what they want to do (i.e. autonomous decision-making), particularly concerning those considering not to participate in CRC screening (46, 50, 51). Additionally, the existing dominant view of cancer screening being a good thing to do could make people less likely to notice, value and remember information that does not fit well with this view, such as information about the possible harms and risk of CRC screening (52-56). This psychological process, as well as the main focus on the benefits of cancer screening, could explain our finding that the public were more aware of the possible benefits of CRC screening than of its possible harms and risks. The public’s focus on the possible benefits of CRC screening, while less aware of or neglecting the possible harms and risks, may indicate that public opinion concerning the CRC screening programme is not based on a full comprehension of what CRC screening entails. This could be a concern in itself as well as in view of individuals having to make an informed CRC screening decision. This potentially not well-informed public opinion may affect people’s personal views and attitude towards CRC screening and, consequently, their personal decision concerning participation (52, 57-59).

**Differences in decision-making between CRC screening participants and non-participants**

Our thesis shows differences in the decision-making process between CRC screening participants and non-participants. Firstly, we found that CRC screening participants had a clear dominant focus on the advantages of CRC screening when deciding about participation, while CRC screening non-participants had no clear focus on either the advantages or disadvantages of CRC screening. Similar to the existing dominant positive view concerning cancer screening, this focus on the advantages could lead to CRC
screening participants noticing and valuing information about the disadvantages of CRC screening less (2, 5, 60, 61), thereby impeding the making of an informed decision (20, 21, 62, 63).

Secondly, we found that for half of the CRC screening participants in our interview study, essentially all that was required to decide to participate was to be invited for the CRC screening programme, as it signalled to them that CRC screening was a good thing to do. Especially CRC screening non-participants, on the other hand, seemed to attribute an important role to information and deliberation as part of their decision-making process. People who decide not to participate in the CRC screening programme may be inclined to seek out more information and to deliberate their decision more than those who decide to participate in it. This may be related to a pressure felt to present sound arguments for not participating in the CRC screening programme as it deviates from the apparent social norm of participating.

Thirdly, our survey study in chapter 6 showed that, although differences are small and it concerns relatively small groups of people, people scoring higher on using a spontaneous decision-making style were more likely to have participated in CRC screening, while people scoring higher on using an avoidant decision-making style were more likely not to have participated in CRC screening. This appears to contrast with the finding in our interview study that non-participants prefer a more rational approach/style. However, there may be different subgroups, namely a group that is well-informed and following deliberation decides not to participate in CRC screening, and a group that prefers to avoid making the decision, resulting in not participating in CRC screening (64). This distinction might also be related to education or health literacy level. In our thesis we found that, in general, a higher education was associated with not participating in CRC screening. However, many other studies found a positive relationship between a lower education/health literacy level and CRC screening non-participation (65-69). Possible explanations for the findings of these other studies are that lower and higher educated groups differ in their knowledge and understanding of the disease and of preventive screening, differ in their motivation for or perceived relevance of preventive screening, and differ in the priorities and practical barriers they
have to deal with (65-69). Further research examining the existence of possible subgroups among CRC screening non-participants is needed.

Fourthly, for CRC screening participants and non-participants, different values were involved in their decision-making process. Although both CRC screening participants and non-participants in our interview study valued their health and a good quality of life, CRC screening participants put more emphasis on living and staying healthy longer and on their future quality of life. Thus, from this perspective, CRC screening participants considered getting themselves screened for colorectal cancer as contributing to what they valued most in life. CRC screening non-participants, on the other hand, put more emphasis on not prematurely being labelled as ill/a patient and on their current quality of life. Thus, from this perspective, CRC screening non-participants considered getting themselves screened for colorectal cancer as not contributing to what they valued most in life. These findings suggest that not all members of the public share the general belief concerned with cancer screening that prevention of cancer and living longer is most valuable in life (10, 70). Therefore, not participating in CRC screening is an authentic and justifiable decision for them. Other studies also suggest that CRC screening non-participants may not consider CRC screening as important or relevant for themselves (71-73).

**Methodological considerations**

Strengths and limitations were discussed for each individual chapter. The most important strength of this thesis is that we used both quantitative and qualitative methods, and that we gained more insight into the perspective of those having to decide in real life about CRC screening participation (in the form of both the eligible CRC screening population and the general public). Additionally, we provided an overview showing that the concepts of attitudes, beliefs and knowledge are not operationalised consistently across studies. The overall methodical limitations of this thesis are outlined in the section below.
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Regarding all studies covered in this thesis (except for chapter 2) there are three main limitations. First, we are aware that the CRC screening uptake of 72% in the Netherlands (74) is relatively high compared to other countries, which might limit the generalizability of the results of this thesis to other countries. However, although the participation rates in other countries are typically lower, a generally positive perception of CRC screening among the eligible screening population is found in these other countries as well, as also reported in chapter 2 (64, 66, 75-79). Second, although CRC screening programmes organised by the government also exist in other countries, this is certainly not the universal method of providing CRC screening, which might thus also limit generalizability of our results. Third, we used a random sample of members of a national internet panel as participants. People who participate in online research may differ in significant ways from people who do not participate in online research, which could also limit generalizability.

Regarding the studies examining the individual decision-making process of the Dutch eligible CRC screening population, there are additional limitations. First, as we conducted a cross-sectional study where people had already decided about CRC screening participation or non-participation, we cannot be sure that this decision in itself did not influence their answers (80). Second, a relatively small proportion of our sample (11%) did not participate in CRC screening. A larger proportion of CRC screening non-participants would have been better with respect to generalizability of our findings, as in 2016 28% of screening invitees chose not to participate (74). Third, generalizability could also be limited by the fact that higher educated people were overrepresented in our sample.

3. Suggestions for future research

*Further developing communication materials regarding becoming informed*

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 (2, 52-54, 56, 60). Future research could focus on how best to
design public communication and education materials to encourage people to become informed about relevant aspects of CRC screening. Knowledge of (subgroups 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 noticed 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 (53, 54, 61, 81). For example, people seem to believe that, regarding cancer screening ‘there is no harm in trying’ and/or that certain harms and risks ‘come with the territory’. Additionally, people consider their quality of life to be important. These beliefs and values should be explicitly acknowledged and directly linked to discussing the fact that cancer screening does indeed involve possible harms and risks, potentially affecting one’s quality of life, which an individual should seriously consider before deciding about participation. However, more knowledge concerning people’s specific goals and values in the context of CRC screening is still required. Additionally, the different goals and values present among CRC screening participants and non-participants (e.g. current quality of life versus future quality of life) should also be considered and specified when developing communication and education materials.

*How to evaluate informed or ‘good’ decision-making concerning CRC/cancer screening*

As previously mentioned, the findings of our thesis indicate that the present, expert-defined, concept of informed decision-making only partly corresponds with how people actually make their CRC screening decision. Therefore, using this concept of informed decision-making, with the Rational Decision model as its underlying framework, to evaluate whether people made a ‘good’ screening decision does not appear to be best suited. Supporting this notion are findings of previous studies showing that people regularly failed to make an informed CRC screening decision according to the commonly used definition, because they did not have sufficient knowledge, or their decision did not match their attitude or preferences, but that they themselves did feel informed and were satisfied with their decision (82, 83). Perhaps aspects other than being knowledgeable, such as decision satisfaction or confidence, better reflect what constitutes as being important in real life for making a ‘good’ screening decision (27, 84, 85). In our interview study, we found that most people considered a ‘good’ CRC
screening decision as one based on both reasoning and intuition, one that ‘felt right’ and one they stand by. Timmermans (1) proposes an alternative definition of informed decision-making, aimed to be more in line with how people make decisions in daily life. According to this definition, an informed decision is: a conscious decision which: 1) is based on relevant information according to the decision-maker; 2) builds on a decision strategy that functions well given the individual’s objective of the decision; 3) enables an individual to pursue the life and goals they want; and 4) is taken in freedom, or at least, the conditions to do so are present. Following this definition, future research recently initiated by Timmermans et al. will focus on developing and validating a new measure for informed decision-making in cancer screening, in which the individual decision-making process as well as the abilities and conditions needed for informed decision-making will be considered. 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 decisions.

**Consistent use of the concepts attitudes, beliefs and knowledge**

Many studies in the field of cancer screening (particularly breast, cervical and colorectal cancer screening) have examined people’s attitudes, beliefs and knowledge, as these are core elements of informed decision-making and popular conceptual frameworks used for examining cancer screening participation (e.g. the Health Belief Model (HBM) (86, 87) and the Theory of Planned Behaviour (TPB) (88)). However, our scoping review in chapter 2 showed that the concepts of attitudes, beliefs and knowledge were not measured consistently across studies, which makes it difficult to compare results and draw overall definitive conclusions. Research in the field of decision-making and cancer screening would benefit from clearer definitions and operationalisations concerning how to assess attitudes, beliefs and knowledge. Especially the interchangeable use of beliefs and knowledge appears problematic. The main difference in the definitions of beliefs and knowledge, as outlined in chapter 2, appears to be that knowledge is a belief that is justified by evidence, usually interpreted as scientific evidence or expert findings. In other words, a belief that is in agreement with what experts view as being true is the
equivalent of having knowledge. Subsequently, a belief that is not in agreement with experts’ views is equivalent to not having knowledge, or in other words is simply a belief. When discussing people’s decisions and behaviour, it could be argued that they would rather rely on what they believe to be true and believe to have as ‘knowledge’ than on scientific facts alone (88-91). Therefore, a solution would be to only speak about measuring people’s beliefs and, in light of being adequately informed, whether they are in agreement with experts’ opinions or not.

4. Reflections and implications regarding public health policy and screening practice

Social norm and different views, goals and values in public communication

With regard to autonomous and informed decision-making, following its current definition, the objective is that people decide to either participate or not participate in CRC screening after careful thought, and because it fits with their personal values and preferences regarding screening (23, 27, 28, 46, 50, 51). 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 (1, 92, 93). 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 – in terms of both content and format – that appeals to how people think and what they believe to be important (53, 54, 61, 81). However, this is not an easy task as the public and eligible CRC screening population consist of different subgroups with different views. For example, with regard to possible CRC screening participants, the main challenge is to communicate about the harms and risks of CRC screening in a manner that fits with their existing ‘frame of mind’ concerning CRC/cancer screening. Regarding those considering not to participate in CRC screening, the main challenge is to gain a better insight into
what they believe to be important concerning health and screening decisions. Challenges also exist concerning how to reach people using a spontaneous or avoidant decision-making style, as they may be making less informed and less considered decisions. Another subgroup to consider is those with a lower education or health literacy level, for whom the processing of complex and large amounts of information might be too demanding (94, 95). For these different subgroups, different types of communication materials might be necessary, as well as a layered structure of information provision (especially in combination with online facilities) (96). 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. Current steps being taken with regard to tailoring information are, for example, involving the eligible screening population in developing communication materials, and the use of narratives (97, 98), animations (99) and video (100). These formats might be more suitable for conveying both factual and experiential information while acknowledging the broader affective and social contexts, including social norms (101). However, more testing is needed in this area and caution is warranted, as this approach could also lead to more persuasion and less informed decisions (102, 103).

**The active role of, and trust put in, the government**

In the Netherlands, as well as in a number of other countries such as the UK and Australia (39, 40), people are actively invited by the government or similar organs to participate in CRC screening and other cancer screenings. In our interview study, we found that for half of the CRC screening participants, essentially all that was required to decide to participate in CRC screening was to be invited, trusting that the government had a reason for offering the screening. This decision can only be a ‘good’ decision if the trust people thereby place in the government, as provider of the cancer screening, is justified. Therefore, being a trustworthy provider of CRC screening is important for organisations involved in CRC screening. This entails providing the public with balanced, comprehensible and transparent information about both the benefits and harms and risks of CRC screening (20, 23, 44). We argue that this also includes addressing the fact that CRC screening exists because on a population level the benefits outweigh the disadvantages, but that it is a different matter whether this is also the case on an
individual level (16, 19, 20). Furthermore, in addition to ‘numbers needed to treat’, attention should also be paid to ‘numbers needed to harm’ (104). A concern might be that this will lead to a lower uptake of CRC screening. However, if this is the result of informed non-participation, we may need to re-evaluate the value and legitimacy of population-based CRC screening in its current form. It may signal a need for more personalised CRC screening where personal preferences and factors such as family history are considered more than is the case at present (105), or for the use of different, less invasive or more accepted, screening methods (106, 107). In both these areas, advancements are already being made, guided by both scientific and societal changes, regarding the future structuring and realisation of CRC screening. In addition, if the objective is for people to make autonomous and well-considered screening decisions, the use of an active invitation strategy might be worth reconsidering as this may have an undesired effect. An active invitation strategy can be effective in eliminating certain practical barriers for participating in CRC screening, which has been shown to be particularly beneficial for people from lower socioeconomic status groups (72, 108, 109). However, this strategy could also contribute to the perpetuation of the existing social norm regarding participation (41-43), as well as a less informed decision about CRC screening participation, especially concerning the possible harms and risks (110).

Introducing a small barrier, such as requesting the stool test themselves, might stimulate people to actively think about their screening decision and consider the possible implications of participating and not participating. However, a downside of this strategy could be that not participating becomes the default option, which could lead to more people opting not to participate (103). Thus, ideally, a balance should be found between removing barriers hindering people from participating in CRC screening and creating the right circumstances to encourage people to actively think about their screening decision.

The rational informed decision-making model in practice

Underlying the present, expert-defined, concept of informed decision-making is the Rational Decision model. This decision model is an example of a normative model, stating how people ought to be making decisions (111, 112). As previously mentioned, the Rational Decision model has been debated since the 1950s, and its practical limitations have been acknowledged (e.g. (30, 31)). A common alternative view of
decision-making is that of the adaptive decision-maker with bounded rationality \((32, 33)\), which has gained increased empirical support \((34)\). Although people’s attention and cognitive capacity is limited, they are also able to optimally use their capacity by adjusting their decision strategy to different contexts \((113)\). The adaptive decision-making model is an example of a descriptive model, describing how people make decisions in real life \((111, 112)\). However, despite the long-standing critique concerning the Rational Decision model and the empirical support gained for the notion of adaptive decision-making, the Rational Decision model still became the underlying framework for the concept of informed decision-making. An explanation could be that in developing, defining and operationalising the concept of informed decision-making, too much emphasis was put on the normative, economic, view of decision-making as well as on the epidemiological approach involved in specifying the benefits and downsides of screening. Research into the psychological processes involved in people’s decision-making in real life appears to have received little or no attention in developing the concept of informed decision-making. Although many studies have shown that adapting to the situation and the use of heuristics can result in ‘good’ decisions, and even better decisions than when using a fully rational decision model, some studies have also shown that this strategy can result in ‘bad’ decisions \((33, 113-117)\). Additionally, some studies have shown that on an aggregated level, the Rational Decision model, even though a normative and not descriptive model, can be of predictive value for people’s behaviour \((93, 118)\). It may be that this aggregated perspective was leading for policy makers and other experts in the field of cancer screening. A well-known perspective described by Friedman \((1953)\), and referenced by many others since, supports this notion. He states that “the relevant question to ask about the ‘assumptions’ of a theory is not whether they are descriptively ‘realistic’, for they never are, but whether they are sufficiently good approximations for the purpose in hand.” \((119)\). From this perspective, the Rational Decision model, compared to the notion of adaptive decision-making, may be providing policy makers and experts in the field of cancer screening with a well-structured, more concrete, accessible starting point for how to define and operationalise informed decision-making \((112)\). Nonetheless, we cannot ignore the fact that, as indicated by the results of this thesis, the present, expert-defined concept of informed decision-making is not entirely reflective of how the CRC screening population makes
their decisions in real life. Furthermore, it is also relevant for those involved in CRC screening policy and practice to consider, and make explicit, the purpose of providing support to people when making their CRC screening decision. Is the purpose that people make a CRC screening decision they consider to be a good decision for themselves? Is the purpose that people make a CRC screening decision that is considered informed according to expert standards? Is the purpose to support people in making an informed decision, or in optimising their decision-making process? 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 they themselves consider to be a good decision, i.e. that it corresponds with their personal goals and values, regarding both the decision itself and the decision-making process. This includes (a form of) being informed, as the target population, similar to experts, also thinks it is important to have basic knowledge concerning CRC screening to better understand the choice-options (i.e. for people to know what they are saying yes or no to).

5. General conclusion

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, partly but not entirely corresponds with how people make their CRC screening decision in real life. People expressed a need for information, but did not need to be fully informed, and factors such as intuition, experiences and life values were also important for making their decision. This is further supported by our sample of the eligible CRC screening population scoring highest on using both a rational and intuitive decision-making style. 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 and positive about its quality. That being said, the existence of a positive public opinion or social norm regarding cancer screening participation could affect an autonomous decision-making process, especially for those considering not to participate 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 exist regarding 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. People are guided by their existing views, goals and values, which is part of human psychology. However, the drawback is that it may lead to biased gathering and processing of information, possibly impeding people from becoming informed about relevant aspects of CRC screening.

Our findings raise the question of whether the concept of informed decision-making, in its current strict form, is something we want to pursue. Additionally, if we want to pursue a form of informed decision-making, it raises the question of how best to accomplish this. This is in line with the critique on the current framework of informed decision-making and the proposed alternative definition of informed decision-making, aiming to be more in line with how people make decisions in daily life and to better attune to the decision-maker’s informational needs, goals, values, and decision strategy (1). Furthermore, the role of intuition in people’s decision-making process should be explicitly addressed. It should be appreciated that following one’s intuition is not equivalent to being uninformed, as it is often based on previous experiences and existing knowledge and values. Public communication is continuously in development and the context in which the CRC screening decision is made is being considered more than was the case in the past when designing information brochures and strategies. Ensuring the use of narratives and similar formats as an integrated part of the public communication strategy is a challenge for future policy and research (44).
HIGHLIGHTS

- The present, expert-defined, concept of informed decision-making does not correspond with how people make their CRC screening decision in real life.
- People express a need for information and use reasoning, but other factors such as intuition, experiences, existing views and life values are also important for making their decision.
- People are generally positive about CRC screening, but they may not be sufficiently informed as more people were aware of the possible benefits of CRC screening than of its possible harms and risks.
- The existence of a positive social norm regarding CRC screening participation could be affecting an autonomous decision-making process, especially for those considering not to participate in CRC screening.
- A responsibility lies with those involved in CRC screening policy and practice to establish being a trustworthy screening provider and to provide the conditions necessary for making an autonomous and informed decision.
- 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 think it is important to have basic knowledge concerning CRC screening.
- Future research could focus on how best to design public communication and education materials to encourage people to become informed about relevant aspects of CRC screening.
- Future research should focus on developing an alternative definition and measure of informed decision-making, aimed to be more in line with how people make decisions in daily life.
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Reference list


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