CHAPTER 1

General Introduction
1. Introduction

Colorectal cancer (CRC) is one of the most common causes of cancer death in developed
countries (1, 2). In the Netherlands, it currently ranks as the third most prevalent cancer
among both men and women (2). Population-based CRC screening is widely
recommended (3-6) as it can reduce the incidence and mortality of CRC (7-10). CRC
screening involves possible benefits, but it also involves possible downsides, such as
false positives, false negatives, overdiagnosis, overtreatment and risks associated with
sigmoidoscopy/colonoscopy (5, 6, 11-14). 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 (15-17). Therefore,
exterts in the field of cancer screening increasingly consider it important that people
make a personal and informed decision concerning CRC screening participation (18, 19).

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 they make their CRC screening decision
and optimise their decision-making process.

Preventive cancer screening

Preventive cancer screening is aimed at healthy individuals who are not experiencing
any symptoms in order to detect cancer in an early stage or precursors of it. Its purpose
is to reduce the number of cancer cases, treatments (invasive and non-invasive) and
cancer deaths. The idea that early cancer has no symptoms and that searching for early
signs could be effective in reducing cancer mortality was already formulated within the
medical community in the beginning of the 20th century (20). It followed the developing
notion that, regarding asymptomatic diseases in general, people could profit from early
detection through widespread preventive screening (21). At first, preventive screening
consisted of periodic health examinations performed by an individual’s personal
physician (22). Early detection through periodic screening in order to improve patient
outcomes appeared logical and had a very intuitive appeal to the medical community,
which contributed to the general approval and uptake into clinical practice. Gradually, large-scale preventive screening began to take form, especially in the second half of the 20th century (23, 24). Subsequently, in 1968, Wilson and Jungner (25) published 10 fundamental principles, which are still being used, intended to guide institutions in deciding about whether a population-based screening test should be introduced. Generally, population-based screening should be aimed at an important health problem, which can be identified at an early stage and for which treatment is more effective at an earlier stage. Additionally, a suitable test or examination that is acceptable to the public should be available and the cost-effectiveness should be considered. Currently, screening for several types of cancer is available in most western countries, the most prevailing being for breast, cervical and colorectal cancer (26-28). In some countries, cancer screening is organised at the national level, such as in the Netherlands, the United Kingdom (UK) or Australia, or at the regional, state or provincial levels, such as in Italy (29, 30). With organised cancer screening, people are actively invited to participate in cancer screening and the uptake is monitored. However, other countries, such as Germany or the United States of America (USA), rely on opportunistic screening (31, 32), where, in essence, the responsibility lies with the individuals themselves to ask their physician to be screened, and the uptake may not be monitored. Nonetheless, in the case of opportunistic screening, a national guideline covering recommendations concerning cancer screening often does exist (32).

Public opinion and existing views
As described in the paragraph above, for over a century now, the notion has prevailed that early detection of cancer through screening is beneficial, and this had a very intuitive appeal for the medical community. Therefore, researching the effectiveness of screening as well as the possible harms and risks associated with it initially received relatively little attention. However, gradually there has been growing attention for rigorously testing the effectiveness of early detection and screening modalities (23). Over time, this had led to more evidence and awareness that cancer screening involves possible benefits, but also possible harms and risks (11, 14, 15). 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 and that they should participate in it (11, 19, 24, 33, 34). Understandably, this was not a hard message to sell as, similar to medical professionals, the idea that identifying cancer early on is good makes sense and appeals to the public as well. Because of this long-held ‘benefit-focused’ communication strategy, it is likely that among the general public there is a preconceived notion, or social norm, that participating in cancer/CRC screening is something positive. As people make their decision concerning CRC screening participation within a social/societal context, it is plausible that this public notion or opinion affects people’s personal views and attitude towards CRC screening and, consequently, their personal decision concerning participation (35-38).

Another aspect to consider is the possible influence of pre-existing notions or views about more general concepts related to CRC screening, such as cancer and preventive screening in general, which the public are likely to have based on previous experiences and knowledge. These pre-existing views could provide the public with a ‘mental framework’, which can be used as a ‘short-cut’ to help understand and evaluate the less familiar and more specific subject of CRC screening by acting as a guide concerning which information is used and how to interpret it (39-43). For example, having pre-existing views of cancer being a serious disease and preventive screening being something positive could help in assessing that colorectal cancer in particular is also a serious disease, and that CRC screening is also something positive. However, as information that fits well with people’s pre-existing notions or views is generally noticed more often and valued more highly, this framework could also possibly affect how well-informed the public become about CRC screening (39-41, 43-45). Pre-existing views of cancer being a serious disease and preventive screening being something positive, for example, could then lead to people noticing and valuing information about the benefits of CRC screening more than information about the harms and risk of CRC screening.

An additional reason to assess public opinion concerning CRC screening is the fact that a considerable amount of Dutch government money is spent on the CRC screening programme. Therefore, it seems important to gain more insight into whether the public are supportive of how this money is spent. Thus far, however, there is limited
knowledge on the opinion and views of the general public concerning CRC screening, as the majority of studies on CRC screening (as well as other cancer screenings) have focused on examining the views of only the eligible CRC screening population within the direct context of individual participation (46-52).

**Autonomous and informed decision-making**

As previously mentioned, there has been a growing awareness of cancer/CRC screening involving possible benefits, but also possible harms and risks. The main benefits of CRC screening are that it can reduce the incidence and mortality of colorectal cancer (7-10). The main possible harms and risks of CRC screening are a false positive test result (i.e. the test falsely indicates that cancer is present), a false negative test result (i.e. the test falsely indicates that no cancer is present), overdiagnosis (i.e. diagnosing an abnormality that would never have produced problems such as cancer), overtreatment (i.e. unnecessary treatment as a result of overdiagnosis or less invasive treatments not being available), and discomfort, pain or risks (e.g. bleeding or perforation of the colon) associated with sigmoidoscopy/colonoscopy (5, 6, 11-14). In general, it is believed that, on a population level, the possible benefits of CRC screening outweigh the possible harms and risks, but whether this is also the case on an individual level is a different matter (11, 14, 15). This is why the concept of autonomous and informed decision-making has been introduced in the field of cancer screening (18, 53). Related to this development is also a societal shift of personal responsibility and autonomous decision-making having become more prominent in Western society today (54, 55). This is also reflected in the introduction of concepts such as empowerment (56), self-management (57) and shared decision-making (58) in the medical and public health domain. The underlying framework for the concept of informed decision-making is the Rational Decision model (59, 60). The Rational Decision model assumes that people base their decision on making maximum use of information and rationally weighing all aspects involved. Additionally, it assumes that people have stable preferences. Following the Rational Decision model, the aim of informed decision-making is that people make a decision concerning CRC screening participation based on a good understanding of the potential benefits and harms of CRC screening combined with their personal situation and preferences (15-19, 53). 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 (18, 61, 62). A central part of an informed decision is also that it is one’s personal and free decision (i.e. autonomous decision).

In the context of cancer screening and CRC screening, both informed and shared decision-making can be encountered. It is important to note that these two concepts are not equivalent to each other. In informed decision-making, it may be that no one else other than the individual it concerns is actively involved in the decision-making process, which is the situation in the Netherlands. It can also be that a physician is merely involved to provide information about screening. In both cases, there is no active, bidirectional discussion between a physician and the decision-maker about the screening information and the decision-maker’s values and preferences. Additionally, individuals are responsible for their own decision. In shared decision-making, however, an active, bidirectional discussion between a physician and the decision-maker is present and the final decision is made jointly. This process could stimulate a broader perspective on the information, values and preferences involved (58, 63).

**CRC screening participation**

Many studies have been conducted on CRC screening participation (see also our scoping review in chapter 2). A main research focus of previous research seems to have been to examine whether an informed decision had been made, therefore focusing on assessing people’s attitudes, beliefs and knowledge concerning CRC screening (i.e. the key elements of informed decision-making). Studies found that people regularly failed to make an informed CRC screening decision according to the commonly used definition described above, because they did not have sufficient knowledge, or their decision did not match their attitude or preferences (64, 65). However, people themselves often did feel informed, were satisfied with their decision, and experienced little decisional conflict (64, 65). This raises the question of how the eligible CRC screening population
makes decisions in practice and when they consider they have made an informed and
‘good’ screening decision.

Another main focus of previous research on CRC screening seems to have been to
examine which reasons and factors were associated with screening uptake or
participation (66, 67). Research on CRC screening participation has often used the Health
Belief Model (HBM) (66) or the Theory of Planned Behaviour (TPB) (52) as a framework.
Within HBM and TPB, the emphasis lies on assessing people’s beliefs, knowledge,
perceived social norm, self-efficacy, and practical barriers, which have all been shown to
be associated with people’s decisions concerning CRC screening participation (52, 66, 68,
69). Some studies also found that people’s experiences, intuition, feelings, and social
support were associated with their decision of whether to participate in CRC screening
or not (16, 66, 69-71). Although these previous studies on CRC screening 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.

Decision-making process
Making a decision or choice can be described as a cognitive process that involves the
processing of (different kinds of) information and evaluating the different choice-
options, which will result in the choosing of one option (72). It is a well-known and
accepted theory that cognitive processes can roughly be divided into two main
categories or systems (i.e. dual processing theory), namely a more intuitive, quick,
effortless and unconscious process (system 1), and a more analytical, systematic,
effortful and conscious process (system 2) (73). The idea is that people use these two
systems next to each other and in combination with each other. However, there is an
ongoing debate about whether these two systems are truly distinct, and about the
extent and manner (i.e. parallel or sequential) in which they interact (74). Nonetheless,
it is evident that different people deal differently with the various decisions in their lives
(72, 74). How an individual approaches a decision could be described as someone’s
decision-making style (75) and is associated with several aspects. For example, it can be
related to personality traits, such as a ‘need-for-cognition’, which would promote a
more informed and thoughtful process (76, 77), or a ‘need-for-closure’, which would promote a more speedy process (78, 79). It can also be context-dependent. For example, a new or more complex decision often invokes a more thoughtful process, while time constraints can stimulate the use of intuition and heuristics as well as being influenced by other people’s behaviour (74, 80, 81). Furthermore, people’s motivation and goals are involved (regarding both their health and the accuracy of their decision). People who, for instance, experience a personal relevance, will be held accountable, or have a reason to be accurate will be more inclined to make an analytical and well-considered decision (74, 80-82). Additionally, people can have specific goals they want to achieve when making health-related decisions, such as becoming healthy or avoiding getting ill, which has been shown to influence their decision and decision-making process (74, 83-89). People’s goals and their orientation or focus surrounding it could affect how they interpret, use and value information concerning CRC screening (42, 88, 90, 91). In this way, people’s goal-orientation/focus could perhaps be seen as a general orientation affecting the relevance of people’s more specific beliefs and considerations concerning CRC screening. Examining people’s decision-making style and goal-orientation/focus regarding CRC screening could provide useful insights for a better understanding of people’s CRC screening decision-making process. However, to our knowledge, these two aspects have received little attention so far in the context of CRC screening, or other cancer screenings.

**Possible differences associated with sociodemographics**
Previous studies on CRC screening have shown that differences in screening participation, attitudes, beliefs, and knowledge are often associated with people’s sex, age, education and health literacy, although findings have not been entirely consistent (49, 52, 65, 66, 92-96). Health literacy concerns people being able to: 1) Access/obtain information relevant to health; 2) Understand information relevant to health; 3) Process/appraise information relevant to health; and 4) Apply/use information relevant to health (97). Research in the field of decision-making has also shown differences in the decision-making process related to age, education and health literacy. Studies in this area found that elderly people tend to use analytical processes less and experiences and heuristics more (92, 98), and that they more often prefer to postpone making their
decision or to leave it up to others (98). Additionally, people with a lower education or low health literacy have potentially more difficulty with processing complex and large amounts of information as part of their decision-making process (95, 96). Considering these previous findings in the field of CRC screening and decision-making, it is possible that among the eligible CRC screening population there are different subgroups of people related to these sociodemographic characteristics, who might need different means of support in making an informed CRC screening decision.

**CRC screening procedure**

In January 2014, a national screening programme for colorectal cancer, provided by the government, was introduced in the Netherlands (99). A national screening programme for breast cancer and cervical cancer already existed, since 1990 and 1996, respectively. The participation rates for both breast cancer screening (most recently, 79% (100)) and cervical cancer screening (most recently, 64% (101)) have been relatively high over the years. Regarding CRC screening, everyone in the Netherlands between the ages of 55 and 76 years old biennially receives an invitation to participate in the CRC screening programme via a self-administered stool test (immunochemical faecal occult blood test: iFOBT), which is paid for by the government. Accompanying this invitation is a brochure with information about CRC screening. People have to decide for themselves whether they want to take part in the CRC screening programme and, thus, perform the stool test (Figure 1, decision 1). Our research focused on examining the decision-making process concerning this decision. The stool test involves collecting a very small amount of one’s own stool, which is then sent to a laboratory to be examined for (microscopic) traces of blood. If the stool test gives a positive result for blood being present, that individual is referred for a colonoscopy to find out if they actually have colorectal cancer or precursors of it. They are invited for an intake at the hospital and then have to decide whether they want to undergo a colonoscopy or not (Figure 1, decision 2). A colonoscopy involves examining the inside of one’s colon to look for abnormalities, making it an invasive test. The costs for a follow-up colonoscopy are covered by people’s health insurance. In 2016, 72% of those invited for the CRC screening programme decided they wanted to be screened (102), which is relatively high compared to other countries.
Figure 1. CRC screening procedure in the Netherlands

Using a stool test as initial screening test, followed potentially by a colonoscopy, is also the approach of screening programmes in some other countries, for instance Australia (103). However, other approaches are also possible. For example, in the United Kingdom people aged 60-75 are offered a stool-test as initial test, while people aged 55-60 are offered a sigmoidoscopy as initial test (which is an internal examination of only part of the colon) (104). Furthermore, in countries that rely on opportunistic screening, such as Germany (31) or the United States (32), people have to decide themselves which screening test they prefer, having to choose mostly between a stool test, sigmoidoscopy or colonoscopy.

2. Objective and overview of this thesis

Within the context of the Dutch CRC screening programme, 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 within which this decision is being made, as this is likely to affect people’s individual decision-making process (36-38). 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.

This thesis starts with a scoping review (chapter 2) on people’s attitudes, beliefs and knowledge (i.e. the key elements of informed decision-making) regarding cancer screening in general, specifically the three most common cancer screenings of breast, cervical and colorectal cancer, as well as how these have been examined/assessed. We aimed to provide a structured overview of the diverse findings surrounding the complex issue of informed decision-making in cancer screening. Chapters 3 and 4 of this thesis describe a survey study into public opinion concerning the Dutch CRC screening programme and related public perceptions. Chapter 5 covers a study into the possible association between people’s goal-orientation, focus on the advantages or disadvantages of CRC screening, main considerations and decision concerning CRC screening participation. In Chapter 6, we examined which decision-making styles the eligible CRC screening population scored highest on using, and if the use of a certain decision-making style was associated with CRC screening participation and people’s evaluation of their decision. Chapter 7 describes a qualitative study where we aimed to examine how the concepts of autonomous and informed decision-making relate to how the eligible CRC screening population actually makes their decision and when they believe they have made a ‘good’ screening decision. Finally, in Chapter 8, the general conclusions are formulated and discussed in relation to scientific literature, public health policy and screening practice.
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