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TO PARTICIPATE OR NOT: DECISION-MAKING AND EXPERIENCES OF INDIVIDUALS INVITED TO SCREENING FOR COLORECTAL CANCER

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To participate or not: Decision-making and experiences of individuals invited to screening for colorectal cancer

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In loving memory of my mother Ann-Charlotte

POPULAR SCIENCE SUMMARY OF THE THESIS

Worldwide, bowel cancer is currently one of the most common and deadly cancers in both women and men. Through screening, a process where apparently healthy individuals undergo some sort of examination to help find and treat the cancer at an early stage, many deaths can though be prevented. Bowel cancer screening may include a stool test and/or an examination where the bowel is investigated from the inside by a flexible tube with a small camera at the end; i.e., a colonoscopy. Target ages for screening vary between countries but usually start in the fifties or sixties.

In Sweden, bowel cancer screening has, to date, only been offered regionally but will soon be implemented nationwide due to the lifesaving evidence. The screening arrangement will be such that individuals aged 60–74 years are offered to send in a stool test for examination, and if this exam shows blood in the stool, a follow-up colonoscopy will be recommended. With this approach, it is estimated that it will be possible to save about 300 lives per year. For this to be realised, however, it is necessary that many people participate. Still, in bowel cancer screening, low participation is often a major concern. It is therefore important to understand why people choose to participate or not in bowel cancer screening, and especially when planning for and designing new screening programmes. In this work, it is also essential to ensure that people can make informed and value-based decisions as to whether or not to participate in the screening; i.e., decisions that are based on relevant knowledge and align with the person's personal values.

Against this background, the overall aim of this thesis is to add to the understanding of factors and experiences associated with participation and non-participation in screening for bowel cancer. To answer this aim, we asked individuals, aged 59–62 years, who had either participated or had elected not to participate in bowel cancer screening as part of a research study (the Screening of Swedish Colons study), to respond to an online survey and to take part in focus group discussions and individual telephone interviews. In the online survey, individuals were questioned about their ability to gain access to, understand, and use health information (i.e., health literacy); anxiety related to screening decision; bowel cancer- and screening knowledge; personal values and preferences; and whether they had involved any healthcare professionals when making their decision about whether or not to participate in the screening. In focus group discussions and individual telephone interviews, individuals were asked to describe their thoughts when they received the screening invitation and their experiences with the screening procedure (i.e., stool test and/or colonoscopy). A total of 1,498 individuals responded to the online survey, of which 1,334 participated in the screening and 164 had declined. Furthermore, 58 individuals took part in either a focus group discussion or an individual telephone interview. Of those, 44 had participated in the screening and 14 had declined.

When this material was analysed, we found that most individuals, irrespective of whether

they had participated in the screening or not, had good health literacy and experienced low anxiety related to their screening decision. Concerning these issues, the groups did not seem to differ in any way. Both groups described pros and cons regarding the screening information materials and demonstrated fairly similar knowledge bases about bowel cancer and bowel cancer screening, which varied depending on the type of question asked. For example, nine out of ten individuals in both groups knew that blood in the stool could be a symptom of bowel cancer, while less than half of each group recognised alcohol, smoking, overweight and physical inactivity as risk factors for the disease. Individuals who had declined screening were less sure about their bowel cancer risk and whether screening could reduce the risk of dying from bowel cancer. When making the decision, those who chose to participate in the screening mostly considered the importance of finding bowel cancer early and worry over bowel cancer, while those not participating mostly considered the risk of discomfort and complications. In both groups, most individuals made their decision without involving a healthcare professional. Screening by stool test was generally met with approval, while colonoscopy screening could be perceived as either bothersome or easy. Making time for the colonoscopy was, for example, easier for those who were either not working, working part-time or for those who could control their working hours.

These results indicate that there is room for improvement in how we communicate about and arrange bowel cancer screening to enable high, informed, and equal participation among the Swedish people. They also suggest that different people have different needs when it comes to screening and can require various types of support throughout the screening process.

ABSTRACT

Background: Colorectal cancer (CRC), the third most common and second most fatal cancer worldwide, can to a large extent be prevented by organised population-based screening. In Sweden, organised CRC screening only operates regionally, yet it is soon to be implemented at the national level with the intention of reducing overall mortality of the disease. CRC screening programme effectiveness is, however, often limited by low rates of participation. Understanding reasons for non-participation is thus crucial, and especially when designing and introducing new screening programmes. Simultaneously, individuals should be able to make informed and value-congruent decisions as to whether or not to participate, and ideally make these decisions through shared decision-making.

Aim: The overall aim of this thesis is to enhance the understanding of factors and experiences associated with participation and non-participation in screening for colorectal cancer.

Methods: To address this aim, both quantitative and qualitative approaches were used. Study participants were recruited from the Screening of Swedish Colons (SCREESCO) trial, in which individuals aged 59–62 had been randomised and invited to participate in either screening by colonoscopy or by faecal immunochemical test (FIT). For Studies **I**–**III**, either part or all of the data were collected using an online survey consisting of four questionnaires: two on health literacy (HL; the Swedish Functional Health Literacy Scale and the Swedish Communicative and Critical Health Literacy Scale; Study **I**); one on anxiety (the State–Trait Anxiety Inventory scale; Study **II**); one on knowledge, values and preferences, and involvement (the SCREESCO questionnaire; Study **III**), for which the responses and scores of screening participants (n = 1,256–1,320) and screening non-participants (n = 153–161) were analysed and compared using descriptive and inferential statistics. Moreover, qualitative data for Studies **I** and **IV**, exploring views about being invited to CRC screening and experiences of the screening procedure, were collected through six focus group discussions (screening participants, n = 24) and 34 individual telephone interviews (screening participants, n = 20; screening non-participants, n = 14), and analysed using inductive qualitative content analysis.

Results: The findings of this thesis showed no differences in HL levels between screening participants and non-participants, with the majority of both groups having adequate HL (Study **I**) and equally expressing pros and cons of the screening information materials (Studies **I**, **IV**). Screening participants and non-participants likewise displayed a similar pattern for CRC- and screening related knowledge, which varied across items; e.g., 90% recognised blood in the stool as a CRC symptom, but less than 50% mentioned overweight, smoking, alcohol, and physical inactivity as CRC risk factors (Study **III**). Screening non-participants were less sure about their CRC risk and the ability of screening to reduce the risk of dying from CRC (Study **III**). In many respects, values and preferences of the groups differed; i.e., while screening participants mostly considered the importance of early detection

and CRC worry when choosing to participate in screening, non-participants took the risk of procedural discomfort and complications under most consideration when choosing to decline (Study **III**). Psychological impact of screening was generally low; i.e., most screening participants and non-participants scored low for anxiety related to the decision and there was no difference in anxiety levels between the groups (Study **II**). Likewise, screening participants were often unconcerned about going through the screening procedure (Study **IV**). Still, some individual characteristics and timepoints of the screening process were associated with experiencing greater anxiety or concerns (Studies **II**, **IV**). In both groups, healthcare professionals were generally not involved in decisional discussions or consulted for information about screening (Study **III**). In established contacts, however, their role was considered important (Studies **III**, **IV**). Undergoing screening by FIT was most often depicted as simple and easy, apart from a few practicalities (Study **IV**). Colonoscopy screening was associated with arduous preparations and pain and also with no discomfort at all (Study **IV**). Both screening procedures were described as interfering with individuals' daily lives, with colonoscopy screening appearing more cumbersome for those who had limited ability to control their working hours (Study **IV**).

Conclusions: In this thesis, most individuals, irrespective of whether they were screening participants or non-participants, had adequate HL, felt well-informed but partially lacked knowledge of CRC and screening, did not involve any healthcare professional in their decision-making, and experienced low levels of anxiety related to their decision. Both groups described pros and cons of the screening information materials but differed in respect to their values and preferences by taking various matters into consideration when deciding whether to undergo screening. Screening participants experienced various emotions and logistical concerns, with the most important being the influence of individuals' work- and life situation for colonoscopy experience. These findings indicate that there is room for improvement in the current communication and arrangement of CRC screening for facilitating high, informed, and equal participation. Furthermore, the results suggest that individuals have various needs and may require different means of support throughout the screening process.

LIST OF SCIENTIFIC PAPERS

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

I. Wangmar J, Jervaeus A, Fritzell K, Wångdahl J, Hultcrantz R, Wengström Y. Health literacy levels and views about being invited to a colorectal cancer screening program. Acta Oncol. 2018 Jun;57(6):743-749.

II. Wangmar J, von Vogelsang AC, Hultcrantz R, Fritzell K, Wengström Y, Jervaeus A. Are anxiety levels associated with the decision to participate in a Swedish colorectal cancer screening programme? A nationwide cross-sectional study. BMJ Open. 2018 Dec 22;8(12):e025109.

III. Wangmar J, Wengström Y, Jervaeus A, Hultcrantz R, Fritzell K. Decision-making about participation in colorectal cancer screening in Sweden: Autonomous, value-dependent but uninformed? Patient Educ Couns. 2021 Apr;104(4):919-926.

IV. Wangmar J, Wengström Y, Jervaeus A, Fritzell K. Two sides of every coin: individuals' experiences of undergoing colorectal cancer screening by faecal immunochemical test and colonoscopy. Eur J Public Health. 2021 Dec 1;31(6):1290-1295.

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LIST OF ABBREVIATIONS

CI	Confidence interval
CRC	Colorectal cancer
FGD	Focus group discussion
FIT	Faecal immunochemical test
gFOBT	Guaiac faecal-occult blood test
FS	Flexible sigmoidoscopy
HL	Health literacy
IQR	Interquartile range
OR	Odds ratio
RCT	Randomised controlled trial
SCREESCO	Screening of Swedish Colons
SDM	Shared decision-making
S-CCHL	Swedish Communicative and Critical Health Literacy scale
S-FHL	Swedish Functional Health Literacy scale
STAI-S	State-Trait Anxiety Inventory S-Anxiety scale
WHO	World Health Organization

1 INTRODUCTION

Cancer rates continue to increase over the world, resulting in physical, emotional, and monetary burdens for individuals, families, populations, and healthcare systems (1). In 2020, approximately 19.3 million new cancer cases and 9.9 million cancer deaths were estimated worldwide. Corresponding numbers for 2040 are anticipated to be 30.2 million and 16.3 million, respectively (2). Historically, the fight against cancer has primarily focused on treating already-developed disease. In recent decades, however, more attention has been given to measures of prevention, which has led to substantial interest in introducing various types of screening programmes during the life course (3). Sweden, for example, has established screening services at the national level for both breast and cervical cancer and is now in the start-up phase for a similar programme for colorectal cancer.

Nurses' work in preventing diseases and promoting the health of individuals and populations goes all the way back to the early work of Florence Nightingale and her systematic acquisition and dissemination of knowledge about how environmental factors impact human health (4). It has since been more or less prominent in nursing theory, education and practice, partly depending on the orientation of nursing science, medical progress and health policy (4). In Sweden today, however, disease prevention and health promotion are recognised as essential parts of nurses' work in promoting equity in care and health (5). Within this effort, consideration must be given to both the perspective of public health and the health of the individual (4). In the context of cancer screening, it has, for example, been suggested that nurses bear responsibility for encouraging screening participation, facilitating access to screening facilities, providing information and education with the aim of supporting individual knowledge and choice, and leading research about screening practices (6). It is my greatest wish that this thesis, encompassing studies of factors and experiences associated with participation and non-participation in colorectal cancer screening, can contribute to this work.

2 BACKGROUND

2.1 SCREENING FOR DISEASE

Screening for disease, together with immunisation, are the two areas where medical interventions have had the most impact on public health (7). As proposed by the World Health Organization (WHO), screening refers to "the presumptive identification of unrecognized disease in an apparently healthy, asymptomatic population by means of tests, examinations or other procedures that can be applied rapidly and easily to the target population" (8). The purpose of screening is to distinguish individuals who either have, or are at higher risk of, a disease from those who do not, in order to provide early treatment or intervention and thus, reduce disease-specific incidence and/or mortality (3). In such a way, screening can have major benefits for population health, however, at the individual level, there are relatively few who will benefit directly from being screened.

For a disease to be subject to screening implementation, several criteria must be met. In Sweden, the recommendation on organised population-based screening of any disease is based on a total of 15 principles issued by the Swedish National Board of Health and Welfare (9). These originate from WHO's classic screening criteria (10), such as the condition being an important health issue, having a recognisable latent phase, and appropriate test procedures and treatment available, yet have been elaborated upon and adapted to better comply with the Swedish healthcare system (9). For example, the Swedish evaluation process also includes issues regarding ethics, organisation, resource needs, and validation of screening information materials. The goal of a national consensus and coordination of screening is healthcare offered on equal terms, referring in part to the idea that all individuals in the targeted population should be given equal opportunity for participation (9). As for general healthcare, however, it is up to each region to organise and implement the recommended screening programme.

2.2 COLORECTAL CANCER

Reviewing colorectal cancer (CRC) from a screening point of view, several facts and features ought to be known. Today, CRC is the third most common cancer and second-leading cause of cancer-related death worldwide. In 2020, there was an estimated rate of over 1.9 million new cases and approximately 935,000 people were expected to die from CRC (11). Incidence rates are about fourfold higher in economically developed countries, with parts of Europe, Northern America and Australia/New Zealand ranked highest (11). The lowest incidence rates are found in regions of Africa and Southern Asia (11), although the number of new cases is on the rise (12). Geographic variations can largely be explained by lifestyle, with poor dietary habits (i.e., high intake of fat and/or red/processed meat and low intake of greens), low physical activity, obesity, smoking and high alcohol consumption suggested to increase one's risk of developing CRC (13-15). Mortality rates are, however, less varied

across world regions due to the implementation of screening programmes and improving treatments (16).

In Sweden, about 6300 individuals are diagnosed with CRC yearly: two thirds with tumours in the colon, and one third with rectal malignancies (17, 18). Similar to the global cancer ranking, CRC in Sweden holds third place in terms of incidence and second in terms of mortality in both sexes (17). In 2020, CRC accounted for more than 2,700 deaths, corresponding to 12% of the total number of deaths caused by cancer that year (19). The lifetime risk of developing the disease is about 5% (20). Men and women are almost equally affected and nearly 80% of individuals are aged 65 years or older (middle age 70 years) at diagnosis (17, 18). The five-year overall survival rate is approximately 66% (20), but highly dependent upon tumour stage at the time of detection, ranging from over 90% for localised stage CRC to less than 5% if the cancer has metastasised (18).

Like for many cancers, the aetiology of CRC is not known in detail though previously declared lifestyle features together with nonmodifiable factors such as advancing age (13, 14), hereditary components (13, 14), inflammatory bowel disease (13, 14) and type 2 diabetes (14) likely are associated with increased CRC risk. The natural history of the disease is, however, reasonably well understood. In the vast majority of cases (>90%), cancer arises from a precancerous polyp (i.e., an abnormal growth of cells within the intestinal mucosa), evolving to an adenoma, progressing to adenocarcinoma through a multi-steps process involving genetic, histological and morphological changes known as the adenoma–carcinoma sequence (14, 21). This development usually takes about 5 to 15 years (14, 21), and is mostly asymptomatic until the cancer has progressed to a more advanced stage (14). However, when symptoms are present, the individual may experience blood in the stool, change in bowel habits, abdominal pain, anaemia, fatigue, and unintended weight loss (21).

2.3 COLORECTAL CANCER SCREENING

Fulfilling WHO's screening criteria (10) including being a public health issue, having a long preclinical phase and adequate test procedures, as well as potentially curative treatment, CRC qualifies for organised population-based screening. The primary purpose of CRC screening is to reduce mortality in the population by finding cancer, or precursor lesions of cancer, at an early and treatable stage. Randomised controlled trials (RCTs) have shown that screening can decrease CRC mortality rates by 16–31% (22). CRC screening is therefore currently recommended as public health policy by several organisations (23), with numerous high-incidence countries having either population-based or opportunistic (i.e., screening upon individual request or after physician recommendation) programmes in place, though screening formats vary (22). Variations mainly include target age range (between 44–75 years), screening intervals, and the choice of screening procedure (22).

Of the several screening procedures available, one of the most common is annual or biennial faecal testing, which currently predominates organised population-based screening programmes (22). In faecal testing, stool is analysed for either haem (i.e., guaiac faecal-occult blood test [gFOBT]) or human globin (i.e., faecal immunochemical test [FIT]) as an indicator of bleeding due to precancerous polyps or cancer (13, 14). Faecal test-based screening has the advantage of being non-invasive, possible to perform at home, and does not require specific bowel preparation (14). However, the procedure can also result in both false-normal (i.e., false-negative) and false-abnormal (i.e., false-positive) test results, needs regular repetition, and always requires additional diagnostic clarification if blood is detected (14).

Another common screening procedure is the colonoscopy, often referred to as the 'gold standard' for detecting CRC (13, 14). For screening purposes, colonoscopies can be used as both a primary and a secondary screening tool (i.e., as a diagnostic follow-up for people with an abnormal test result from another screening procedure) (24). When used as a primary screening tool it is often offered either singularly or in 10-year intervals (13, 14). Benefits of the colonoscopy procedure include its high sensitivity, the fact that it provides a visualisation of the whole colon, and allows for the removal of precancerous and small cancerous lesions at the time of detection (14). Nevertheless, it is also invasive, time-consuming, costly, and involves extensive bowel preparation. Likewise, colonoscopy screening may require the use of sedation or anaesthesia, and can, albeit rarely, result in harm such as bowel perforation and post-procedure bleeding (14).

With features similar to colonoscopy, flexible sigmoidoscopy (FS) offered either singularly or every five years is a third CRC screening alternative (13, 14). FS needs less extensive bowel preparation, only examines the distal part of the bowel and requires a follow-up colonoscopy if leisons are found (14). Other procedures, less frequently utilised, include computed tomographic colonography, multitarget stool DNA testing, colon capsule endoscopy, and magnetic resounance colonography (13).

2.4 COLORECTAL CANCER SCREENING IN SWEDEN

In Sweden, organised population-based CRC screening is, at present, only established in the healthcare region of Stockholm-Gotland, offering men and women aged 60–70 years screening for blood in the stool every two years using a home testing kit (initially gFOBT but FIT since 2015), including a follow-up colonoscopy if blood is detected. The programme, which is centrally administrated and began in 2008, was initiated based on the European Union Council's 2003 screening recommendations, advocating faecal test-based screening in the average-risk population aged 50–74 years (20). The Swedish National Board of Health and Welfare, on the other hand, did not consider there to be sufficient evidence to endorse such a proposition, and stated in 2011 that CRC screening was a continuing subject for research and development (25). In response to this decree, the Screening of Swedish Colons

(SCREESCO) study was proposed and designed.

The SCREESCO trial was a three-armed RCT operating in Sweden during the 2014–2020 (26). The study was conducted on behalf of the Swedish Ministry of Health and Social Affairs, with the primary aim of investigating the efficiency of screening on CRC mortality in the Swedish population, but also what screening procedure would be best. Secondary aims included investigating CRC incidence, health economic aspects, screening adherence and associated factors, and experiences from the perspectives of both screening participants and non-participants, some of whom were included in this thesis. In total, the trial engaged 33 hospitals, 18 regions, 6 regional cancer centres, and 273,000 Swedish residents. Eligible individuals were identified from the Swedish total population register, randomised, and invited to either screening by FIT (n = 60,000), screening by colonoscopy (n = 30,500), or to serve as control subjects (i.e., not invited to any screening procedure but monitored through the Swedish cancer register and the Swedish causes of death register, n = 183,000). Inclusion criteria for taking part in the trial were individuals aged 59–62 who were living in Sweden. Residents of Stockholm, Gotland and Västernorrland regions, participants in the NordICC trial, and individuals with a CRC or anal cancer diagnosis were excluded. Follow-up time for mortality and incidence has been set to 15 years, while other outcomes are evaluated on an ongoing basis (26).

At the same time that the SCREESCO trial started recruiting study participants, the Swedish National Board of Health and Welfare revised their recommendations on CRC screening. The reason behind this decision was the growing evidence for gFOBT screening demonstrating a 15% reduction in CRC mortality in the studied populations, which in Sweden would translate to the prevention of about 300 deaths a year. Hence, since 2014, biennial faecal test-based screening for individuals aged 60–74 years is recommended in Sweden (25, 27). The introduction of a nationwide programme was thus suggested to wait for the inclusion of individuals to the SCREESCO trial, but is now under way with a gradual start-up from 2021.

2.5 PARTICIPATION IN COLORECTAL CANCER SCREENING

For a screening programme to be successful and truly have an impact on population mortality and public health, high participation rates are essential. According to the European guidelines for quality assurance in CRC screening, a participation rate of at least 65% is considered desirable (28). WHO poses an even stricter criteria and claims that rates over 70% are necessary for a screening programme to be effective (8). Nonetheless, low uptake is one of the major challenges in screening for CRC (29), and participation rates in CRC screening are significantly lower than those of other cancer screening programmes (30). This also applies to Sweden, although the differences have become somewhat smaller. In the Swedish breast cancer screening setting, the overall uptake has been reported to be about 80% but varies across different regions and sociodemographic groups (31, 32). Similar patterns have been

identified for cervical cancer screening (33), with a general participation rate of 71% (32). In the CRC screening programme of Stockholm–Gotland, which has over 10 years' experience, uptake has traditionally been around 60% (34, 35), yet has in recent years been reaching rates of 70% (32). Lower participation has been confirmed in men (34, 35) and individuals younger than 65 years (35). Against this background, it is reasonable to believe that CRC screening uptake will differ across regions and subgroups when introduced nationally. Understanding reasons for non-participation is therefore crucial, especially in light of factors that should be taken into consideration when planning and developing new screening programmes (e.g., choice of screening procedure, screening information materials, support functions etc.) (28). This to aid the implementation of a programme that enables as many people as possible to participate, which also pertains to aspects of equity.

2.6 SHARED DECISION-MAKING

Today, it is well acknowledged that the provision of screening must not only consider the perspective of public health, but also the perspective of the individual (28). Such a commitment partly includes promoting the ability of individuals to make an informed and value-congruent decision as to whether to participate in screening (28). For this purpose, shared decision-making (SDM) is increasingly recognised as the ideal model (36, 37), and will thus, constitute a basis for discussion of the thesis results.

The general idea of SDM is that individuals facing healthcare should be informed as to their healthcare-related options, including risks and benefits, and further encouraged to participate in decision-making regarding their care (38). This is also consistent with the essentials of health-promotive nursing in Sweden (5), and what is stipulated in Swedish law (i.e., the Patient Act) (39). Historically, SDM has been important in the shift from a paternalistic approach where healthcare professionals dictated the rules, to more democratic decision-making recognising individuals' preferences and autonomy (40, 41), and is today considered a key component of person-centred care (42). The term was first described in research literature in the early 1970s but had its major breakthrough with a conceptual paper by Charles et al. in 1997 (43), who initially defined SDM as a treatment decision-making model allowing the patient and the clinician to be equally active in the decision-making process. Suggested key characteristics of the model included the involvement of at least two participants (the patient and clinician), a two-way informational knowledge exchange, the patient's values and preferences, interactional deliberation, and agreement as to what treatment to implement (40, 43). This framework originated in the context of treatment decision-making in life-threatening diseases, however, it has since been further developed and discussed in other decision-making contexts, such as primary care (44).

Today, there are several definitions of SDM and consensus is lacking as to its meaning (38). However, it has been acknowledged that the meaning and function of SDM is likely to differ

across different cultural and clinical contexts (45). In the present thesis, SDM is defined as a decision-making process based on *information and knowledge* about the disease, treatment and screening service including different options; *values and preferences,* including attitudes, beliefs and behaviours related to those aspects; and *involvement* in decision-making, referring to engagement of both the individual and others, including healthcare professionals. The current definition, developed within our research group, originated from the conceptualisation by Charles et al. (40, 43, 44), but was adopted to the screening context based in part on previous qualitative findings from the SCREESCO trial (46). Thus, the definition does not limit involvement to face-to-face encounters or mutual engagement of the individual and the healthcare professional in all steps of decision-making. Instead, forms and levels of interaction are understood to depend on individual preference. As such, our definition is more in line with the SDM definition proposed by the US Preventative Services Task Force (47).

2.7 WHAT CAN INFLUENCE PARTICIPATION IN COLORECTAL CANCER SCREENING?

2.7.1 Health literacy

For the individual facing a CRC screening decision, the process often starts with receiving an invitation letter and then having to process some form of written information, which is when the study of health literacy (HL) becomes relevant. As defined by WHO (48), HL refers to "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health". The concept can be divided into: 'functional HL', addressing the basic reading and writing skills needed to operate efficiently in daily activities; 'communicative HL', referring to the literacy skills and the social and cognitive abilities used to actively participate in everyday life, select information, gain meaning from various communications forms and apply new information when circumstances are changing; and 'critical HL', covering the cognitive and social abilities necessary to critically analyse information and make use of it to gain greater control over situations and life events (49, 50). Thus, recognising HL as a complex phenomenon, these abilities are considered dynamic and context-dependent (51). HL can thereby be understood as a product of personal skills and the systems in which one exists, including the ways in which healthcare information is communicated.

In cancer screening research, there is a tendency of inadequate HL being associated with lower participation rates (52). Still, results vary and are somewhat limited by methodological constraints, such as HL being measured with various instruments, of which some only assess a subsample of skills (52). For CRC screening, limited HL has been reported to be associated with non-participation in organised gFOBT screening (53, 54) and among adults older than 65 years (55). However, in other studies (56-58) and in a younger population (50–64 years) (55), no such association was found. As regards Sweden, no studies on the topic have been conducted.

2.7.2 Anxiety

Whether the decision to participate in screening is associated with anxiety appears to vary across screening programmes and cancer types (59). In CRC screening, there are several aspects that might give rise to concerns, such as being personally responsible for collecting a faecal sample or facing the fact that colonoscopy and FS are associated with certain risks (28). However, research on anxiety and CRC screening is contrary and has mainly been conducted on individuals choosing to participate in the screening (59). In previous studies including screening non-participants, some authors have identified anxiety related to pre-procedure preparations (60) and anticipated test burdens (61-64) as two major barriers for participation in endoscopic screening (i.e., colonoscopy or FS). Yet, others have concluded that they are only minor contributors in the decision to decline (65). Similarly, anticipated anxiety while waiting for the screening result (66), worries about test unpleasantness (61, 66) and fear of the test result coming back as abnormal (61, 63, 66) have been reported as key reasons for non-participation in screening by gFOBT. Neither of the quantitative studies on the topic (61-63), however, have assessed anxiety with a validated measure, and no Swedish studies in the area have been performed.

2.7.3 Aspects of shared decision-making

2.7.3.1 Information and knowledge

Lack of knowledge about CRC and screening, mainly assessed by questions about associated risk factors, incidence, symptoms, prognosis and awareness of screening recommendations and procedures, has frequently been cited as impeding screening uptake (66-68). Nonetheless, public awareness of CRC is generally low across European studies (68, 69). In previous work in the SCREESCO trial, screening participants and non-participants equally stated in focus group discussions and individual interviews that they perceived their knowledge of CRC to be limited (46). Both groups addressed societal values, including insufficient information as the main reasons; however, they did not describe the knowledge- or information gaps in detail (46). Hence, further investigation using other methodological approaches is needed to garner a deeper understanding of what is known and what is not known about CRC and screening from the perspective of the general public, and whether people's knowledge about CRC and screening procedures is associated with their decision to participate in CRC screening.

2.7.3.2 Values and preferences

Individuals' values and preferences have been described as playing a significant role in cancer screening decision-making and thereby screening uptake (70). Within the field of CRC screening, most research on values and preferences have thus focused on preferences regarding the accuracy and features of screening procedures (71-74). Nonetheless, it has been suggested that the values and preferences of screening participants differ from those of non-participants (72). This is supported by early findings from the SCREESCO trial in which, for example, screening participants associated participation with the idea of controlling one's

health, while opposite non-participants had a more fatalistic approach (46). Furthermore, the groups prioritised screening differently (46). Though only examined in a relatively small sample of individuals, the values and preferences of Swedish people facing CRC screening decisions merits further exploration.

2.7.3.3 Involvement

As individuals' preferences may vary on screening procedures, they may also differ for roles and involvement in screening decisions. Internationally, physician recommendation has often been reported to predict CRC screening participation, while insufficient time to discuss CRC screening and a lack of physician's reminders have been stressed as hindrances to screening adoption (68). In Sweden, however, qualitative research from the SCREESCO trial (46) and from the setting of breast cancer screening (75) suggest that individuals who are facing screening decisions favour autonomous decision-making (i.e., making decisions on their own). Thus, subsequent quantitative studies are needed to confirm these findings and to better understand the extent to which they apply to a larger population.

2.7.4 Experiences of the screening procedure

As screening programmes must be widely accepted to be effective, it is not only important to focus on the process of decision-making but also on individuals' experiences of the screening procedures. Although research is limited, and completely lacking from the Swedish context, faecal testing as a CRC screening strategy has been described as being generally met with approval (76-78), with FIT slightly outdoing gFOBT in terms of perceptions of discomfort and overall burden (78). However, in a study on patterns of participation in a FIT-based programme, individuals with a prior negative test experience (e.g., finding it embarrassing or unpleasant) were more likely to not participate in the screening or to drop out (79). Likewise, individuals experiencing greater test burden of faecal testing (FIT and gFOBT) have been found to be less willing to attend another screening round and to recommend the procedure to family and friends (78). With regard to experiences of screening colonoscopies, several studies have been conducted (80-84). In these studies, individuals were reported to be overall satisfied with their colonoscopy (81, 82, 84), yet also to experience embarrassment (80, 82, 83), discomfort during the colonoscopy procedure (80-84), post-colonoscopy pain (81, 82), burden due to pre-procedural bowel preparations (80, 82), and disruptions of daily routines (80, 82, 84). Overall, most of the studies have been carried out using a quantitative approach (78-82, 84).

3 RATIONALE FOR THESIS

CRC represents a substantial part of the global cancer burden yet is largely preventable by organised population-based screening. A prerequisite for screening programmes to be effective is high participation rates, however, uptake in CRC screening seldom reaches desirable levels. In Sweden, organised CRC screening has for a long time only been running in the healthcare region of Stockholm–Gotland but is now to be implemented nationally with gradual start-up beginning in 2021. To facilitate implementation of a screening programme that enables as many people as possible to participate, it is important to understand reasons for non-participation. At the same time, individuals should be able to make informed and value-congruent decisions as to whether or not to participate. It has been suggested from previous research that there are important factors to consider, including individuals' HL, anxiety, aspects of SDM, and experiences of the screening procedure, to achieve high participation in CRC screening. Still, those areas remain understudied in the Swedish context.

4 AIMS

The overall aim of this thesis is to enhance the understanding of factors and experiences associated with participation and non-participation in screening for CRC.

Specific aims for the included studies (**I**–**IV**) were as follows:

I. To explore health literacy levels and views about being invited to screening, among screening participants and non-participants in a national CRC screening programme.

II. To investigate anxiety levels related to the decision to participate or not in a CRC screening programme among screening participants and non-participants, and further to explore associations between higher levels of anxiety related to the decision and individuals' sociodemographic and personal characteristics.

III. To investigate knowledge, values and preferences, and involvement among screening participants and non-participants in relation to CRC and screening decision.

IV. To explore how individuals in CRC screening experience the screening procedure.

5 METHODS

5.1 DESIGN

The overall design of this thesis is descriptive, and encompasses studies with both quantitative and qualitative approaches. Study **I** was conducted using a mixed-methods approach with a triangulation of complementary findings (85), Studies **II** and **III** were cross-sectional survey studies, and Study **IV** was designed according to the principles of qualitative description (86). An overview of study designs and methods can be seen in Table 1.

Table 1. Overview of study designs and methods included in the thesis (Studies I–IV).

Study	Design	Study participants	Measures for data collection	Data analyses
I	Mixed methods	Screening participants (quantitative data, *n* = 1,311, 1,302; qualitative data *n* = 44) Screening non-participants (quantitative data, *n* = 158, 160; qualitative data, *n* = 14)	Demographic and clinical data S-FHL[a] S-CCHL[b] Focus group discussions Individual telephone interviews	Descriptive statistics Chi-square test Qualitative content analysis with an inductive approach
II	Cross-sectional survey	Screening participants (*n* = 1,256) Screening non-participants (*n* = 153)	Demographic and clinical data S-FHL[a] S-CCHL[b] STAI S-Anxiety scale[c]	Descriptive statistics Cronbach's α Independent samples t-test Logistic regression analysis
III	Cross-sectional survey	Screening participants (*n* = 1,320) Screening non-participants (*n* = 161)	Demographic and clinical data SCREESCO questionnaire	Descriptive statistics Chi-square test Mann–Whitney U test
IV	Qualitative description	Individuals who had underwent screening by either FIT and/or colonoscopy (*n* = 44)	Demographic and clinical data Focus group discussions Individual telephone interviews	Descriptive statistics Qualitative content analysis with an inductive approach

[a]The Swedish Functional Health Literacy scale
[b]The Swedish Communicative and Critical Health Literacy scale
[c]The State-Trait Anxiety Inventory S-Anxiety scale

5.2 SAMPLE AND SETTING

The studies of this thesis form part of a larger sub-study within the SCREESCO trial, from which all eligble individuals were identified and recruited. All participants were aged 59–62 years and living in Sweden, with the exception of the Stockholm, Gotland and Västernorrland regions. None had previously been diagnosed with CRC or anal cancer.

According to the arrangement of the SCREESCO trial, all eligible individuals had been invited to screening by a postal invitation, written in Swedish, consisting of an information letter and a coloured-picture leaflet on CRC, CRC screening, and the trial itself. Along with the invitation, individuals randomised to FIT screening received two FIT testing kits and a pre-paid return envelope. Individuals randomised to colonoscopy screening received the invitation together with information that they would obtain a separate letter from an affiliated hospital in their residency area, with a date and time for a colonoscopy appointment. Eight

weeks after the invitation, written screening reminders were sent to those who had not had a FIT result registred at the laboratory and to those who had not confirmed their scheduled colonoscopy. All mailings were coordinated and sent from a central IT system located at the main secretariat of the study. In case of questions or concerns about the trial, a study coordinator was available for telephone contact.

5.2.1 Studies I-III

For the quantitative part of Study **I** and Studies **II** and **III**, a random sample of 2,748 individuals was drawn from the following four groups in the SCREESCO trial and invited to participate in an online survey: screening participants randomised to FIT with a normal test result (n = 749); screening participants randomised to FIT with an abnormal test result (n = 750); screening participants who had been randomised and had undergone a colonoscopy (n = 500); and screening non-participants regardless of randomisation (FIT or colonoscopy; n = 749). Screening participants with an abnormal FIT result could either have completed, declined, or have been awaiting their follow-up colonoscopy. Screening non-participants consisted of individuals who had actively declined screening. The sample was drawn in autumn 2015, from all individuals who had been invited to the SCREESCO trial since the study began in 2014 and represented all 18 member regions. No stratification was performed. The gender distribution was fairly equal, with women comprising 52% of the total sample. A flow chart covering study participant recruitment and the collection of questionnaire data can be seen in Figure 1.

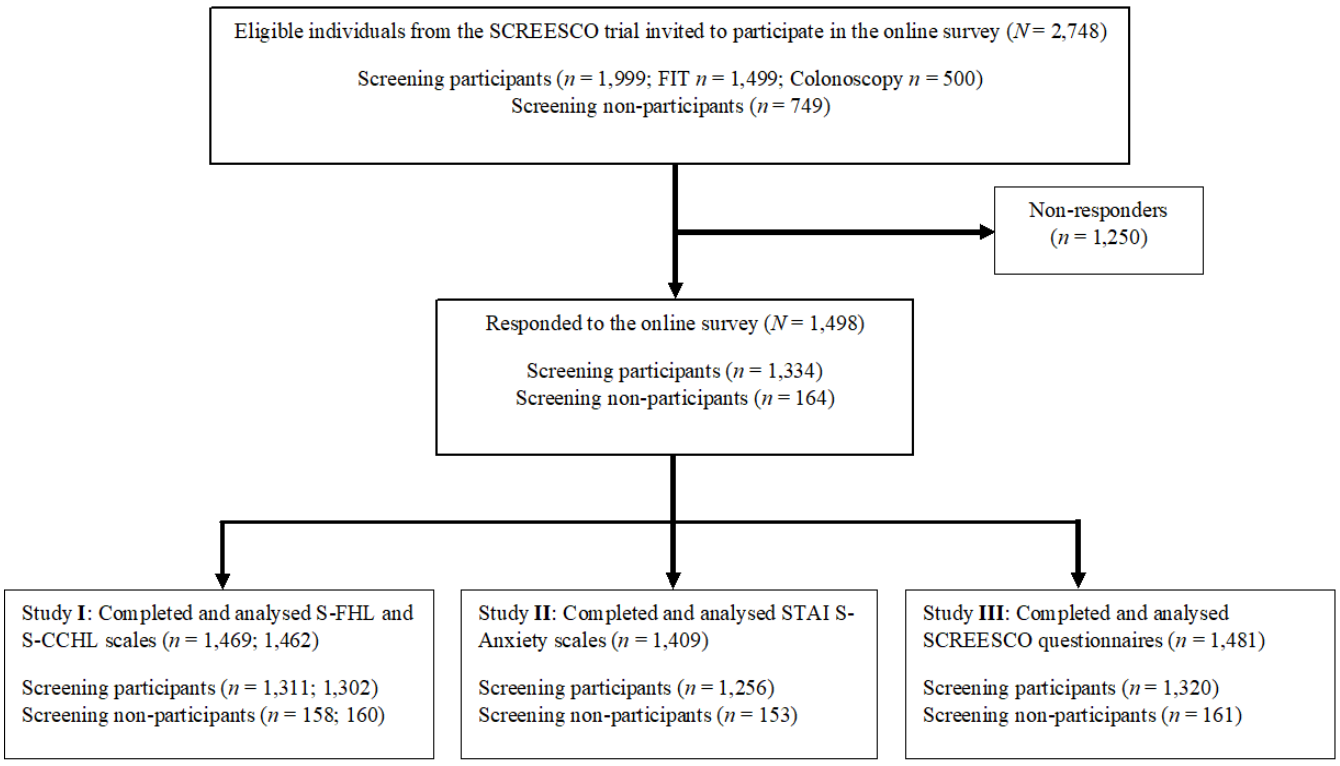

Figure 1. Flow chart of the recruitment of study participants and collection of questionnaire data (Studies I–III)

5.2.2 Studies I and IV

For the qualitative part of Study **I** and Study **IV**, a total of 136 individuals randomised to either FIT or colonoscopy in the SCREESCO trial who had undergone screening, and 34 individuals randomised to either FIT or colonoscopy in the SCREESCO trial who had declined screening (relevant to Study **I** only), were purposively sampled and invited to take part in a focus group discussion (FGD) or an individual telephone interview. Recruitment occurred on an ongoing basis in 2014 and for the purpose of heterogeneity efforts were made to include individuals of both genders and from both rural and urban areas.

5.3 DATA COLLECTION

Two sets of data collection served as the basis for the studies: one quantitative online survey (Studies **I**–**III**) and one series of FGDs and individual telephone interviews (Studies **I**, **IV**). The online survey was pilot-tested in a group of 100 individuals before roll-out (approximately half of them replied), which resulted in minor changes.

5.3.1 Studies I-III

5.3.1.1 Procedure

During a time period of seven months, from October 2015 to April 2016, an invitation letter with a request for participation in an online survey was sent to eligible individuals by mail. The invitation letter was written in Swedish and included study information, log-in details to the survey URL, and contact information for both the research group and for technical support. Those who wished to participate in the study were offered the opportunity to respond to the survey either online or by telephone with help from one of the researchers. Overall, the survey was accessible for completion from October 2015 to June 2016, with no reminders sent. All study participants gave informed consent online prior to entering the study questions.

5.3.1.2 Measures

The online survey consisted of a set of demographic and clinical questions, four questionnaires, two of which assessed HL (Study **I**), one assessed anxiety (Study **II**), and one assessed knowledge, values and preferences, and involvement (Study **III**), and a free text field. Demographic and clinical data were collected using single-answer questions on gender, living situation, education level, occupation, previous experience of faecal testing, and previous experience of colonoscopy.

In Study **I,** HL was explored using the Swedish Functional Health Literacy (S-FHL) scale (87) and the Swedish Communicative and Critical Health Literacy (S-CCHL) scale (88), both of which have been translated from Japanese into Swedish and culturally adapted to the

Swedish context for the purpose of use in health promotion. The scales consist of five items each measuring different aspects of HL: from basic reading skills, such as visual ability and understanding of words and concepts (S-FHL scale), to more advanced abilities of collecting, valuing, and applying health information to everyday life (S-CCHL scale). The items are self-rated on a five-point scale of 'never' to 'always' in a negative direction for the S-FHL scale, and from 'strongly disagree' to 'strongly agree' in a positive direction for the S-CCHL scale. In the analyses, responses are re-categorised into three different levels by assigning new values (i.e., the value of 1, 100, or 1000). These, in turn, are summed up to a total score, for which sums above 1000 are interpreted as inadequate FHL/CCHL. Both scales have been successfully tested for aspects of validity and reliability among Swedish-speaking individuals (87, 88). Further, they have been evaluated for construct validity in the current study population using exploratory factor analysis as part of the coursework of this thesis, with results supporting the unidimensionality of both scales (unpublished data).

To investigate anxiety levels related to screening decision in Study **II**, the Swedish version of the State-Trait Anxiety Inventory (STAI) S-Anxiety scale, translated by Forsberg and colleagues, was used (89). The STAI S-Anxiety scale is a widely-used instrument containing 20 items assessing the presence and severity of different anxiety symptoms (e.g., tension, nervousness, worry etc.) in a specific situation or at a certain point of time, i.e., state anxiety. The items are self-rated on a four-point scale ranging from 'not at all' to 'very much', which are added to get a total score. Higher scores indicate higher levels of anxiety (min 20–max 80). The STAI S-Anxiety scale has been tested and validated for the Swedish context (90), and was further evaluated using Cronbach's alpha in the study population of concern, demonstrating good internal consistency with a coefficient of 0.945 (91).

In order to study knowledge, values and preferences, and involvement in Study **III**, the SCREESCO questionnaire was used. The SCREESCO questionnaire was originally based on the North American DECISIONS Survey; CRC screening module (92, 93) but has been translated and culturally adapted to the Swedish context through work by members of the research group, with the overall goal of assessing aspects of SDM in CRC screening (94). As of today, the questionnaire includes 24 items divided into three subscales: *information/knowledge* (12 items covering knowledge about CRC screening procedures/risk factors/symptoms/incidence- and fatality rates etc.); *values/preferences* (9 items covering the degree to which the decision to participate or not to participate took into account CRC worry/the importance of finding cancer early/risk for discomfort and complications etc.); and *involvement* (3 items including whether any healthcare professional was consulted for a screening decision discussion or information, and if so, the importance of that/those persons(s) as an information source). All items are self-rated with response options varying between questions (e.g., 0–10-point scales, yes/no/don't know-questions etc.) (94). The questionnaire has been psychometrically evaluated in the current study population using the Rasch approach (95).

5.3.2 Studies I and IV

5.3.2.1 Procedure

During a one-year period, from May 2014 to May 2015, eligible individuals were sent a postal invitation, written in Swedish, containing study information and a request for study participation. Screening participants were invited to take part in a FGD while screening non-participants, for ethical reasons, were invited to an individual telephone interview. One week after invitation, one of the researchers telephoned invited individuals to ask about their interest in participating and to schedule a date and time for the FGD or telephone interview take place. Screening participants who liked to participate but who were unable or unwilling to attend a FGD were offered the choice of taking part an individual telephone interview instead, according to the same arrangement made for screening non-participants. Those participating in FGDs filled in an informed consent form at the beginning of each session, and individuals participating in telephone interviews gave verbal consent prior to the collection of demographic and clinical data, and audio-recording.

5.3.2.2 Measures

Demographic and clinical data on gender, education level, occupation and previous experience of colonoscopy were obtained from either the individuals' personal identity number or from self-report.

Qualitative data were collected through FGDs and individual telephone interviews covering three overall topics including the open-ended questions "Can you describe your thoughts when you received the invitation to participate in the CRC screening programme?" (Study **I**) and "How did you experience the screening procedure?" (Study **IV**). A total of six FGDs with two to five participants in each group, and 34 individual telephone interviews (screening participants, $n = 20$; screening non-participants, $n = 14$) were conducted by two members of the research group, both with extensive experience in qualitative methods and gastroenterology. The FGDs were held at different hospitals in various parts of Sweden, and lasted from 31–50 minutes, with a median length of 40 minutes. Individual telephone interviews with screening participants lasted from 4–22 minutes, with a median length of 8 minutes. For screening non-participants, the corresponding duration was 6–22 minutes, with a median length of 11 minutes. To ensure coverage of the basic lines of content, a semi-structed interview guide with open-ended questions was used, including follow-up questions to increase the depth of responses. All data collection was audio-recorded and transcribed verbatim.

5.4 DATA ANALYSES

All statistical analyses were performed in the Statistical Package for Social Sciences (SPSS, Chicago, IL) version 24–26, with a significance level set at $p \leq .05$. In all studies, the

demographic and clinical data of screening participants and non-participants were summarised and, when applicable, compared using the Chi-square test (Studies **I**–**III**). For Studies **I** and **II**, only individuals with complete HL or anxiety scales were included in the main statistical analyses, while individuals in Study **III** were included in all analyses of items for which they had provided a response considered valid. Missing questionnaire data were generally low; i.e., ranging from 1.8–5.9% (Studies **I**–**III**).

5.4.1 Study I

For each individual, HL levels were calculated according to the S-FHL and S-CCHL manuals (87, 88), by first adding a numerical value of 1, 100 or 1000 to each response alternative. For the S-FHL scale, the value of 1 was given to the responses 'never' and 'seldom'; 100 to the alternative 'sometimes'; and 1000 to the responses 'often' and 'always' (87) Reversed for the S-CCHL scale, the value of 1000 was given to the responses 'strongly disagree' and 'disagree'; 100 to the alternative 'partially agree'; and 1 to the responses 'agree' and 'strongly agree'(88). Values were then summarised and dichotomised, with sums above 1000 interpreted as inadequate HL and sums below 1000 interpreted as adequate HL for both scales (87, 88). To compare HL levels between screening participants and non-participants, a Chi-square test was applied.

The analysis of qualitative data on views regarding the screening invitation, performed by three members of the research group, followed the stepwise description of inductive qualitative content analysis proposed by Elo and Kyngäs (96). Data from the FGDs and telephone interviews were analysed together through a process of repeated readings, open coding, and categorisation of codes according to differences and similarities in content. Material from screening participants and non-participants were analysed separately. The later steps of the analysis, i.e., the creation and naming of categories, were discussed among the researchers until a final agreement was achieved.

5.4.2 Study II

A STAI S-Anxiety sum score was computed for each respondent. As the data were normally distributed, an independent samples t-test was applied to investigate possible differences in anxiety levels related to screening decision between screening participants and non-participants. Further, by dividing individuals into two groups by the clinically significant anxiety cut-off value of 40, possible associations regarding anxiety levels and sociodemographic and personal characteristics were explored using logistic regression analysis (STAI S-Anxiety ≥40 coded as 1). Nine independent variables were included in the logistic regression model: screening decision, gender, living situation, occupation, educational level, functional HL, communicative and critical HL, previous experience of faecal testing, and previous experience of colonoscopy. The calculation of HL levels was

done according to the S-FHL and CCHL-manuals (87, 88), as described for Study **I.**

5.4.3 Study III

Screening participants and non-participants' responses on each of the 24 items in the SCREESCO questionnaire were descriptively analysed through the calculation of frequencies, proportions, medians, and quartiles. Due to the outcome of the previous Rasch analysis (95), significance testing was performed at an item level. In nominal level items fulfilling the minimum expected cell frequency criteria, the responses of screening participants and non-participants were compared with the Chi-square test. Corresponding comparisons for ordinal level items were performed with the Mann–Whitney U test. Individuals who had provided double responses on single-answer items or contradictory responses on multiple-answer items (e.g., answering that one had consulted a physician, while at the same time answering that no consultation was performed) were excluded from the analyses concerned. Responses regarding CRC incidence and fatality, specified from 0–100% in 10%-intervals, were categorised into correct, under-, and overestimated answers according to recent statistics (97) and previous classification (95), since it was not considered meaningful to report them separately. Similarly, and for the same reason, responses on stopping age for screening were categorised as either correct or incorrect (95). 'Do not know' responses were included in the analyses of nominal level items from the *information/knowledge* subscale, but not in any other analyses.

5.4.4 Study IV

FGD- and individual telephone interview transcripts were analysed according to Graneheim and Lundman's (98) principles for inductive qualitative content analysis of manifest content. At first, FGD transcripts were read thoroughly and repeatedly to get a sense of the whole. Second, meaning units describing individuals' experiences of the screening procedure were marked, condensed, and labelled with a code close to the original text. Thereafter, codes with similar content were grouped into subcategories. The process was then repeated for the individual interview transcripts, from which the generated codes hence were added to the subcategorisation of FGD data due to considerable similarities in content. Eventually, subcategories were abstracted into categories based on the idea of mutual exclusiveness. The steps up to and including coding were primarily performed by one researcher, yet continually reviewed and discussed in group meetings with the three co-researchers. Final categorisation and naming of subcategories and categories were done jointly.

6 ETHICAL CONSIDERATIONS

When conducting research on human beings, it is important to do so in an ethical manner (99). Thus, the studies in this thesis were carried out with consideration of the ethical principles of the Declaration of Helsinki (100) and with approval from the Regional Ethical Review Board in Stockholm, Sweden (No. 2012/2058-31/3). Still, there are some potential issues within this project that merit reflection.

Approaching individuals to ask about their experiences of being invited to, deciding about, and participating in CRC screening is important for the development and implementation of a screening programme that enables as many people as possible to participate, and thus is in line with the goal of human research: to do good for society and the individuals within it (99). However, making further contact with individuals who have already declined to take part in research, as with those who had declined to be screened within the SCREESCO trial, is not entirely unproblematic with respect to their integrity and privacy. Simultaneously, it is of ethical value to give those people an opportunity to make their voice heard. Yet recognising this ethical tension, several actions were taken throughout the data collection process in this project to protect the privacy and integrity of the screening non-participants as far as possible. No reminders were sent for the online survey and no non-response analyses were performed to compare those who had responded to the online survey to those who did not (Studies **I**–**III**). Additionally, qualitative data from screening non-participants were only collected through individual telephone interviews, as it was not considered ethical to ask them to make the effort to discuss with others in focus groups (Study **I**).

In the recruitment of study participants, all eligible individuals received written information about the studies according to ethical standards (100), stating the research goals, the method for data collection, the voluntariness of participation, that non-participation or withdrawal would not affect any present or future care, and that the data collected would be handled confidentially. For individuals invited to take part in a FGD or an individual telephone interview, corresponding information was also given verbally. Efforts were made to keep the language of the study information simple and neutral. Among those who chose to participate in the studies, informed consent was obtained before any data were collected, i.e., in written format for the online survey (Studies **I**–**III**) and for individuals taking part in a FGD (Studies **I**, **IV**), and verbally for those taking part in an individual telephone interview (Studies **I**, **IV**). However, as often, the study information was only provided in Swedish, which is an ethical dilemma in and of itself, as it means that individuals with language barriers were not given equal opportunity for participation in the project. Thus, this is something to consider in future studies.

Regarding the content of the online survey, respondents were asked to reflect upon several issues that could possibly bring forth unpleasant feelings, such as one's perceived risk of developing CRC and potential anxiety related to the decision to participate in the screening or

not. Taking this into consideration, all study participants were provided with a telephone number to one of the researchers and encouraged to make contact if any concerns were to arise. This possibility of telephone contact also made it workable for individuals with limited access to or who were uncomfortable using computer to participate, as they could get help from the researchers in filling in their responses (Studies **I**–**III**). Moreover, sharing personal experiences of, for example, the screening procedure in a FGD with others might be considered sensitive to some (Study **IV**). Therefore, it was decided to offer individuals who were reluctant to participate in a FGD the opportunity of taking part in an individual telephone interview instead. This also applied to individuals who expressed their willingness for participating in the studies but, for some other reason, could not attend any FGD session. Still, using FGDs to explore potential sensitive topics can be beneficial; when moderated by trained researchers, groups of people sharing the same experience tend to confide and elaborate more than in one-to-one interviews (101). It can also be rewarding for those participating. In this case, FGDs were carried out by researchers who were familiar with both the topic and the method, and participants were perceived to talk effortlessly about their experiences (Study **IV**).

Several measures were taken to carefully protect individuals' identities throughout the project. Before any data were processed or analysed, each person was assigned a study code to deidentify any personal information, and the data collected were stored safely according to existing legislation and local guidelines (102). In the FGDs, the importance of confidentiality was stressed in the beginning of each session, and for the qualitative parts of the project, attempts were made to avoid too detailed quotations and descriptions of the respondents when reporting results (Studies **I**, **IV**). Decisions and actions throughout the studies have continuously been documented in the Karolinska Institutet's electronic notebook (ELN), and in an attempt to make the research freely available, all papers have been published in open access.

7 RESULTS

Overall, there were many similarities concerning the decision-making and experiences of screening participants and non-participants in the studies in this thesis. Therefore, the results are mainly presented under headings including data from both groups, yet with accompanying figures and tables to illustrate some of the outcomes in which they differed.

7.1 DEMOGRAPHIC CHARACTERISTICS OF STUDY PARTICIPANTS

A total of 1,498 individuals (55% of all invited) responded to the online survey serving as the basis for the quantitative part of Study **I,** and Studies **II** and **III**. The majority (*n* = 1,477, 99%) answered the survey online, while 77 chose to respond by telephone with a researcher's support. Of those responding, 1,334 had participated in the screening (FIT screening with a normal test result, *n* = 535; FIT screening with an abnormal test result, *n* = 485; colonoscopy screening, *n* = 314), and 164 had declined. Screening participants and non-participants were similar with respect to demographic data, except for gender, with a significantly higher proportion of women responding in the screening non-participant group (50 vs. 63%, *p* =.003). In both groups, about three quarters were cohabiting and working, and approximately three-fifths were educated up to and including high school level. For full presentation of demographic data of survey responders, please see Paper **I**, Table 1.

Furthermore, 58 individuals agreed to participate in the collection of qualitative data, analysed in Studies **I** and **IV**. Forty-four of those were screening participants, of which 24 took part in a focus group discussion (i.e., six occasions with two to five participants in each group) and 20 participated in an individual telephone interview. In addition, individual telephone interviews were held with 14 screening non-participants (only included in Study **I**). Demographic characteristics of the respondents are shown in Table 2.

Table 2. Demographic characteristics of study participants taking part in focus group discussions and individual telephone interviews (Studies I, IV)

	Screening participants *n* = 44	**Screening non-participants *n* = 14**
Gender, *n*		
Women	20	7
Men	24	7
Level of education, *n*[a]		
Compulsory school	4	3
High school	20	6
Vocational high school	3	1
University	11	4
Current occupation, *n*[a]		
Working	34	12
Seeking employment	1	
On disability living allowance	3	1
Housewife		1
Previous experience of colonoscopy, *n*[a]		
Yes	9	4
No	29	10

[a] Different total *n* due to missing data.

7.2 HEALTH LITERACY AND VIEWS ABOUT SCREENING INFORMATION MATERIALS

Aspects pertaining to HL and views about screening information materials were present in three of four of the included studies.

In Study **I**, it was found that approximately 90% of both screening participants and non-participants scored at levels consistent with adequate HL on the HL scales, with no significant differences in either levels of functional HL or communicative and critical HL between the two groups (p =.664 and .182, respectively). Similarities were also noted in how they perceived the screening invitation, with both groups describing pros and cons. In favour of the invitation, screening participants and non-participants equally had a positive outlook towards it, perceived it as easy to grasp, and considered the content and research context to be clearly described. Both groups valued and appreciated being able to choose among different information sources, such as combining reading the information letter and the coloured picture leaflet or by making a telephone call. In case further information was warranted, some screening participants mentioned searching the internet. This usage of the internet as a source of information was similarly reported by 17% of screening participants and 12% of non-participants in Study **III**, who equally rated its importance as high (Mdn 8, IQR 5–9 in both groups, p =.579). However, as per the disadvantages of the invitation, some screening participants found the invitation difficult to comprehend, perceived it as heavy reading, and needed help from others to be able to assimilate the content. Additionally, some screening non-participants felt that the invitation was formulated in a compelling or patronising manner, contained too much text, did not draw enough attention, or had an insufficiently clear message (Study **I**).

Aspects of clarity were also addressed among screening participants in Study **IV** for instructions and communication of screening results. While instructions on the FIT and bowel preparation were perceived as straightforward, information about potential burdens of bowel preparation, eating and drinking restrictions in connection to the colonoscopy, and overall time requirements was considered lacking. Furthermore, routines for communicating screening results were deemed unclear; i.e., individuals sometimes neither knew whether they had gotten the result or whether, or when, it was something to expect. Still, among those who had noted their written FIT result, it was appreciated that the result was communicated in terms of being normal or abnormal instead of being positive or negative. Further, the need for a follow-up colonoscopy was recognised to be stated clearly (Study **IV**).

7.3 COLORECTAL CANCER- AND SCREENING RELATED KNOWLEDGE, INCLUDING RISK PERCEPTIONS

With regard to knowledge, as investigated in Study **III**, screening participants and non-participants scored at the upper half and equally high on the 0–10-point scale for feeling informed about CRC screening (Mdn 7, IQR 6–9 in both groups, p =.579). Still, general

performance on the knowledge questions varied.

Concerning disease-specific knowledge, approximately 20% of respondents in both groups correctly estimated the percentage of Swedish individuals that will be diagnosed with CRC during their lifetime, while more than 45% overestimated incidence trends. Almost as many (>40%) underestimated the diagnosed proportion of individuals who will die from the disease. On both questions, another third of the individuals in each group reported that they did not know. Diet was the most commonly considered factor of importance in CRC development, cited by approximately 80% of the members of both groups. This was followed by heredity and advancing age, with the former reported by almost 70%, and the latter by 66% vs. 58% of screening participants and non-participants, respectively. Equally, less than 50% thought of overweight, smoking, alcohol, and physical inactivity as important CRC contributors. In terms of risk perceptions, screening non-participants were significantly more often unsure about their risk of developing CRC while, on the other hand, screening participants significantly more often rated their CRC risk as average (Figure 2). The proportion of individuals perceiving their risk to be either high or low was equally distributed between the groups (Figure 2). In both groups, nearly nine in ten individuals were aware that blood in the stool could be a symptom of CRC, and correspondingly one half and one third, respectively, recognised change in bowel habits and abdominal pain as CRC symptoms.

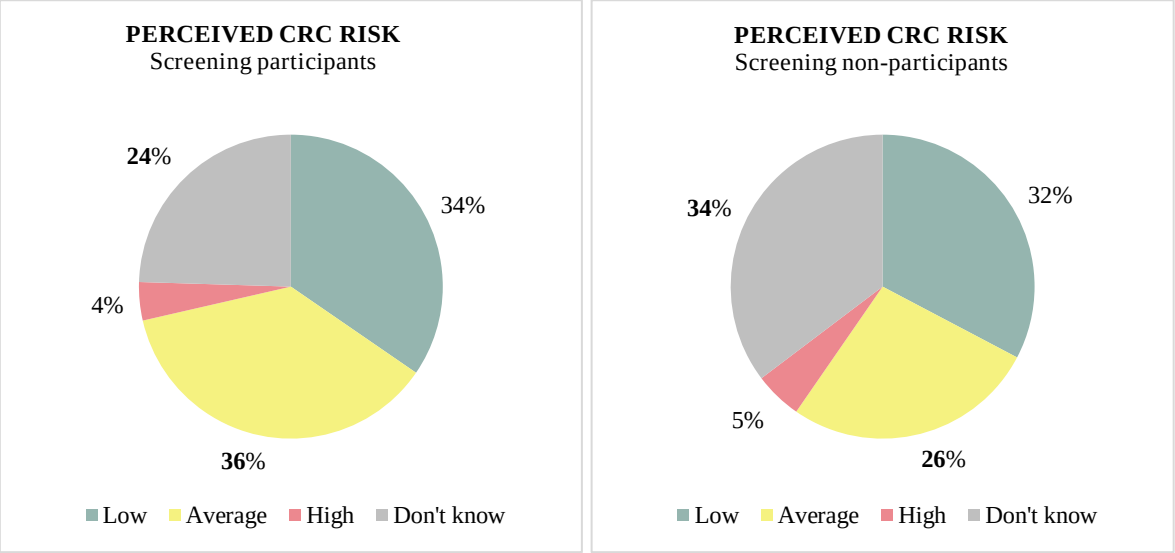

Figure 2. Perceived colorectal cancer (CRC) risk among screening participants and non-participants with significant differences ($p \leq .05$) according to the Chi-square test marked in bold (Study III)

As regards screening knowledge, more than 65% of both screening participants and non-participants recognised colonoscopy and faecal testing as CRC screening procedures. Compared with screening participants, non-participants were significantly less convinced that regular screening reduces the risk of dying from CRC (Figure 3). The number of correct responses on stopping age for CRC screening was low in both groups (Study **III**).

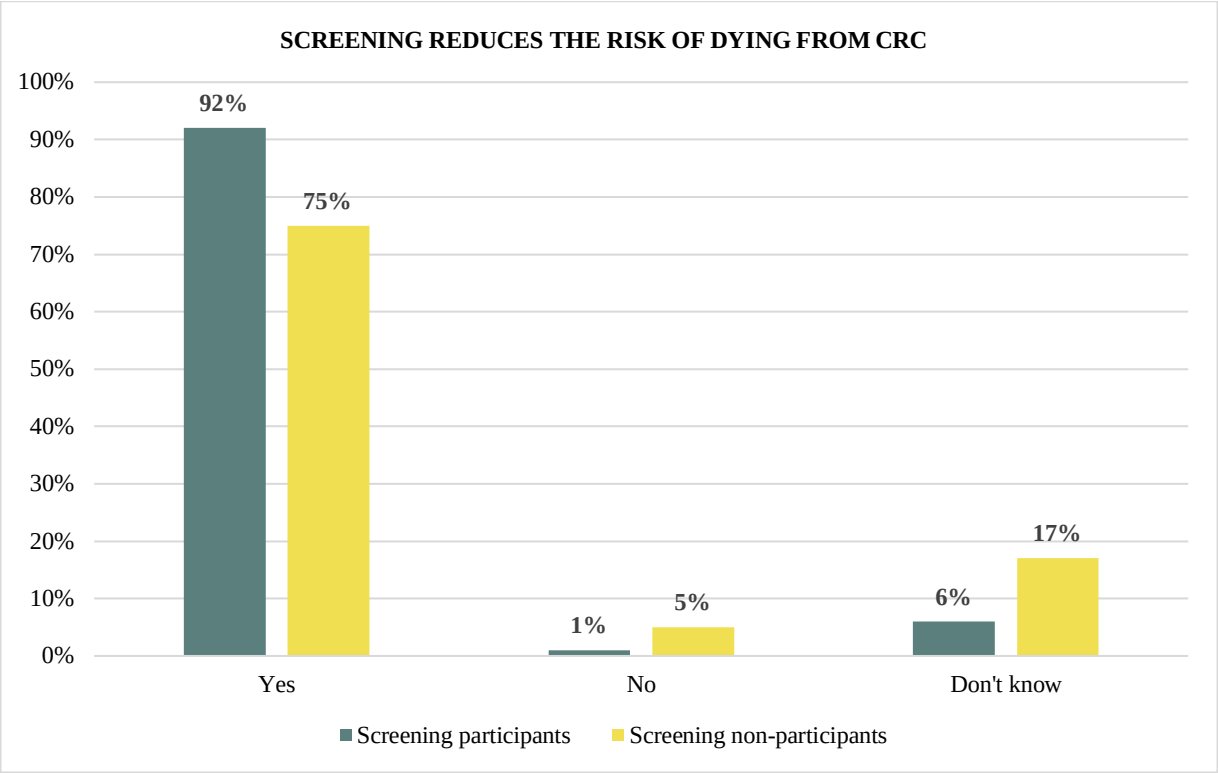

Figure 3. Assumption that screening can reduce the risk of dying from colorectal cancer (CRC) among screening participants and non-participants with significant differences ($p \leq .05$) according to the Chi-square test marked in bold (Study III)

7.4 VALUES AND PREFERENCES IN DECISION-MAKING

In many respects, the values and preferences of screening participants significantly differed from those of non-participants. For example, when asked about issues taken into consideration in decision-making in Study **III**, reported on a 0–10-point scale ranging from *took no consideration* to *took great consideration*, screening participants displayed the highest median scores for the importance of finding CRC early and CRC worry. Screening non-participants, on the other hand, scored highest for the risk of discomfort and complications related to the screening procedure (Table 3). Compared with screening participants, they also scored higher for the idea that taking part in the screening would be time consuming, while scoring lower for the risk of receiving a false-abnormal test result and that the screening procedure was free of charge (Table 3). Nonetheless, they showed similar behaviour in approaching of significant others for information prior to decision-making, with the majority (>65%) not conferring with someone close. Among those who did, their importance was thus rated equally high in both groups (Mdn 8, IQR 5–9 vs. 5.5–9.5, p =.941; Study **III**).

Table 3. Significant differences in values and preferences of screening participants and non-participants[a]

When you made your decision to participate or not in the bowel cancer screening, to what degree did you consider…[b]	**Screening participants**	**Screening non-participants**
	Mdn (Q1; Q3)	Mdn (Q1; Q3)
… bowel cancer worry?	7 (3; 9)	3 (0;7)
… the importance of finding bowel cancer early?	10 (9; 10)	5 (2; 9)
… that your test can indicate bowel cancer when it is not true (e.g., false alarm)?	4 (0; 7)	2 (0; 5)
… risk of complications due to the bowel examination?	2 (0; 5)	7 (2; 9)
… risk of discomfort due to the bowel examination?	3 (0.25;6)	8 (5; 10)
… that your participation would be time consuming?	2 (0; 5)	5 (0; 9)
… that the test was free of charge?	2 (0; 6)	0 (0; 2)

[a] Tested for differences in medians by the Mann–Whitney U test with *p*-values = <.001–.003
[b] Response options ranging from 0 = *took no consideration* –10 = *took great consideration*

7.5 THE ROLE OF HEALTHCARE PROFESSIONALS

In Study **III,** findings showed that healthcare professionals were generally not involved in decisional discussions about screening, but in about 17% of cases with screening participants and 31% of cases with non-participants. In those occasions, screening participants most frequently talked to healthcare professionals other than physicians and registered nurses, while non-participants most often consulted registered nurses (Figure 4). Similar patterns were seen for the use of healthcare professionals as a source of information about screening, used by approximately 17% and 22%, respectively. However, when done, healthcare professionals were rated high in terms of importance in both groups (Mdn 8, IQR 7–10 vs. Mdn 9, IQR 5.75–10, p =.973; Study **III**). Other situations throughout the screening process, in which healthcare professionals were depicted as important, noted in Study **IV**, included psychological counselling upon the receipt of an abnormal FIT result. Furthermore, in the tasks of verbally informing individuals as to what was happening during the colonoscopy, creating an easy-going atmosphere, and reducing colonoscopy-related pain and discomfort. In regard to colonoscopy screening, it was also expressed that one would have appreciated a contact person for questions as the colonoscopy approached (Study **IV**).

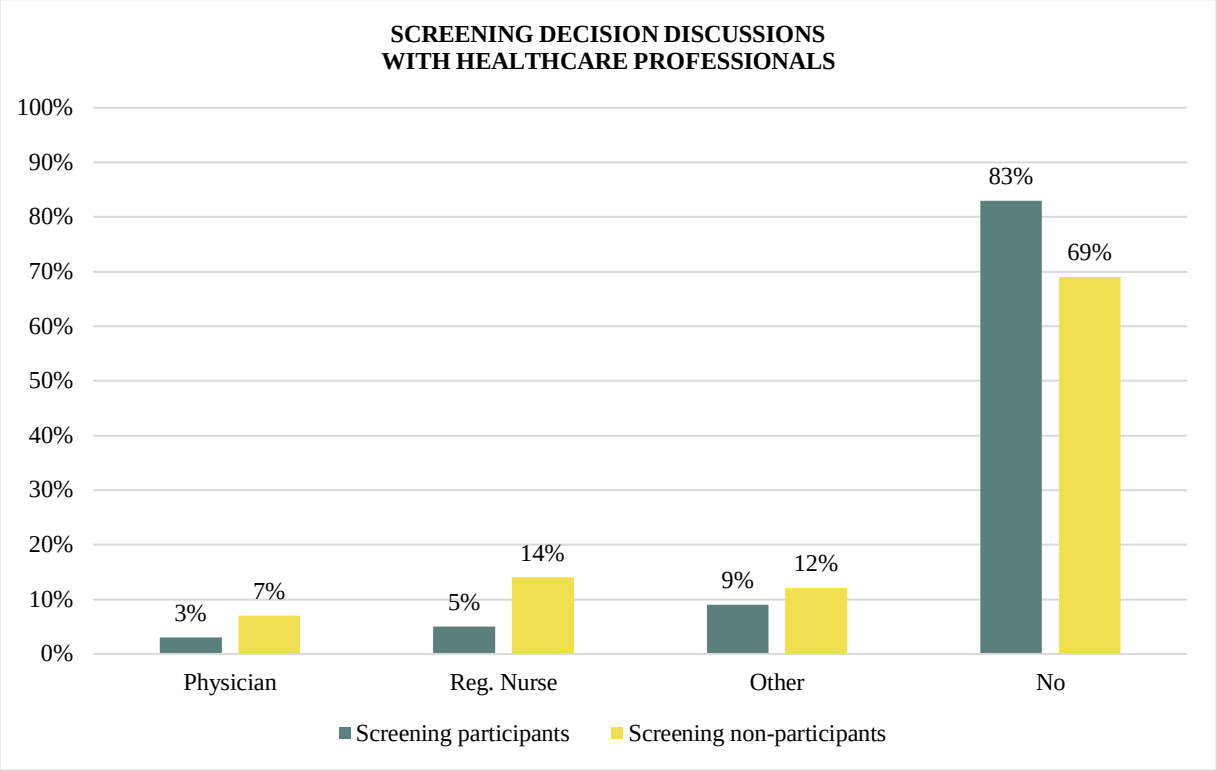

Figure 4. Screening decision discussions carried out with healthcare professionals among screening participants and non-participants (comparisons not statistically evaluated; Study III)

7.6 PSYCHOLOGICAL IMPACT OF SCREENING

The psychological impact of screening was addressed in several of the studies. Results from Study **II** showed that the decision to participate or not to participate in the screening was in most cases (79%) not associated with higher levels of anxiety, and no significant difference was observed for the mean anxiety score of screening participants and non-participants (STAI S-Anxiety mean score 34.1 vs. 33.9, p =.859). Still, in the logistic regression analysis, women and individuals with a previous experience of faecal testing displayed greater odds of reporting higher anxiety levels, i.e., a STAI S-Anxiety score ≥40, associated with their decision (OR = 1.37, CI 1.04–1.80, p =.025 and OR = 1.53, CI 1.14–2.05, p =.004, respectively). In opposite, lower odds were found for those who were cohabiting (OR = 0.65, CI 0.48–0.88, p =.005), working (OR = 0.72, CI 0.53–0.96, p =.027), or having adequate HL (FHL: OR = 0.49, CI 0.33–0.73, p <.001 and CCHL: OR = 0.55, CI 0.38–0.82, p =.003; Study **II**).

As previously reported, CRC worry was rated as an important contributor to the decision to participate in the screening in Study **III**. However, in individual telephone interviews and FGDs analysed in Study **IV**, screening participants often described that they were rather unconcerned about going through the screening procedure, as they were feeling healthy, confident, and calm about the situation, or in- or out of control regarding their health. They also expressed various concerns, and at different times during the process, such as preprocedural worry about the outcome of screening, stress during bowel preparation, colonoscopy-related concerns, shock of receiving an abnormal FIT result and subsequent worry while waiting for the follow-up colonoscopy (Study **IV**).

7.7 EXPERIENCES RELATED TO THE LOGISTICS OF FAECAL IMMUNOCHEMICAL TEST AND COLONOSCOPY

Results from Study **IV** demonstrated that screening participants experienced varying concerns related to the logistics of the screening procedure, with the FIT being mostly described as simple and easy, yet also as unnecessarily complicated regarding the use of collection paper and management of loose stool. It was also stressed as demanding to have to do the sampling twice. Among individuals who had undergone a colonoscopy, bowel preparation was predominantly expressed as the worst part owing to, for example, the large volumes they were required to ingest, the time requirements, the need to fast, and the presence of nausea and vomiting. The laxative was also experienced to have an unpleasant taste, smell, and texture. Still, others experienced no such discomfort. Similar patterns were found for the colonoscopy itself, with some experiencing it as painful and unpleasant, especially during tube insertion and when changing direction of the tube, while others perceived it as rather uncomplicated. Additionally, following the procedure on screen awakened both feelings of disgust and amusement. Post-colonoscopy, physical after-effects such as headache, tiredness, and changes of bowel habits and the stool were reported by a few participants. With all facts on hand, several expressed that the screening procedure was experienced as either worse or better than they had expected; i.e., conducting the FIT was only for the better, while colonoscopy screening could be either/or.

For both FIT and colonoscopy screening, individuals described how the screening procedure interfered with their daily lives, forcing them to plan and reschedule other activities. Work- and life situation was particularly essential to how easy it was for individuals to make time for the colonoscopy, in such a way that it was to the advantage of those able to control their working hours, working part-time, or not working at all. Performance was also facilitated when individuals were able to influence their appointment time. In other cases, individuals had to take vacation, stress to work or drive car after the procedure, which in some cases forced participants to abstain from sedation (Study **IV**).

8 DISCUSSION

8.1 DISCUSSION OF MAIN RESULTS

The overall aim of this thesis was to enhance the understanding of factors and experiences associated with participation and non-participation in screening for CRC. Altogether, the results of the four included studies demonstrated that most individuals had adequate HL, felt well informed but lacked some knowledge about CRC and CRC screening, did not involve any healthcare professional in their decision-making, and experienced low levels of anxiety related to their screening decision. This was evident for both screening participants and non-participants. The most important difference between the groups was in relation to their values and preferences. For those who participated in the screening, either by having a FIT and/or a colonoscopy, varying emotions and logistical concerns were prominent. In the following sections, these findings, including the clinical implications of the results, will be discussed both in relation to uptake in CRC screening and from the perspective of SDM.

In this thesis, participation and non-participation in screening was not associated with individuals' level of HL. Pertaining to both functional as well as communicative and critical HL skills, most screening participants and non-participants scored at an adequate HL level on the HL scales, with no significant differences in HL levels between the two groups. Similarities between the groups were also noted for the qualitative findings regarding views about the screening invitation. These results point towards the idea that HL might not be the most successful area to intervene in terms of improving the uptake of CRC screening among the Swedish population. However, they contribute to important insights for the development of screening information materials that are understandable and helpful for individuals in making an informed decision as to whether to participate in screening, taking aspects of HL into account.

Although the majority of individuals who were interviewed for this thesis had positive experiences with the screening invitation, some considered it to contain too much text, to include somewhat heavy reading, and to be difficult to grasp. Given that the screening was conducted as part of a research study, the invitation of concern did not only include information about the actual screening but also about the SCREESCO trial itself. Thus, it was more extensive than screening invitations typically are. At the same time, there were those who felt the need to seek additional information on their own, which demonstrates the difficulty of balancing the amount of information included in letters of this kind. To offer various information sources that consider the different needs of the targeted population will thus likely be important as part of the introduction of nationwide CRC screening. From such a perspective, our results suggest that the internet may be an important but under-used channel of communication, that can be complementary to more analogue formats. Furthermore, efforts must be made to ensure the use of plain and simple text in future invitation letters. In this regard, using short sentences, concrete words, and explanations of words that are uncommon has been found to be helpful to everyone, regardless of their HL level, and to result in more well-informed decisions about CRC screening (103). According to our findings, this is also essential to consider in the design of screening instructions and in the written communication of screening results; i.e., by, for example, labelling screening

results as either normal or abnormal. Carefully choosing words and expressions is further important, as certain wording in the invitation letter made some screening non-participants feel like they were obliged to participate or that they were addressed in a condescending manner, which may impede their willingness to participate in the screening. Screening non-participants also stressed the importance of receiving invitations that quickly draw one's attention. In the Netherlands, the invitation to CRC screening is sealed in a purple envelope to stand out from other postal mails. Most Swedes are probably familiar with this approach, yet not from the screening context, but in terms of annually receiving the orange envelope from the Swedish Pensions Agency. Thus, changing envelope colour could possibly be a relatively simple measure to attract more attention to screening letters as well.

Like HL, screening participants and non-participants demonstrated fairly similar patterns for CRC- and screening-related knowledge in this thesis, albeit with a few exceptions. Overall, individuals scored high for feeling informed about CRC screening but performed unevenly on the knowledge items. For example, about 90% in both groups recognised blood in the stool as a symptom of CRC, while less than 50% were aware of overweight, smoking, alcohol, and physical inactivity as CRC risk factors. In addition, both groups widely overestimated the percentage of individuals that will be diagnosed with CRC during their lifetime, and underestimated case-fatality rates. Compared with screening participants, non-participants were significantly less convinced as to the ability of screening to reduce the risk of dying from CRC and less confident about their CRC risk. At item level, these findings provide useful insights into areas where efforts can be made to increase public knowledge about CRC and CRC screening and thus facilitate the ability of people to make informed decisions as to whether or not to participate in screening. One way to communicate probabilistic information more clearly could, for example, be to include visual aids (e.g., graphs or icon arrays) in screening information materials (104). Additionally, there is evidence that incorporating personalised risk communication can support both knowledge gain and, to some extent, screening uptake (105). However, as recognised by others (106), drawing conclusions from these kinds of results is challenging, as different studies use different questions and methods for assessing knowledge, and also interpret outcomes differently in terms of what constitutes having adequate understanding (106-108). Moreover, there might be a discrepancy in what is regarded as sufficient knowledge for making an informed decision about screening from the perspective of healthcare professionals and the general public (including between individuals). Such divergences have been reported before, with the conclusion that healthcare professionals place greater emphasis on the utilisation of CRC screening information than do screening invitees (109). Consequently, this is something that merits further discussion and attention in the Swedish screening setting.

As found in previous qualitative findings from the SCREESCO trial (46), the values and preferences of screening participants and non-participants differed significantly in this thesis. Herein, in such a way that they took different matters into consideration when making their decision to participate or not, i.e., while screening participants took into most consideration the importance of early CRC detection and worry over CRC, non-participants placed the greatest emphasis on the risk of discomfort or complications due to the screening procedure. Similar results have been recently reported from the Dutch CRC screening programme, in which screening participants were found to weigh more heavily on the possible advantages of

screening when deciding to participate, while non-participants opposite weighed more heavily on the potential harms (110). Both groups considered the decision on screening to reflect their life values (110). These results indicate that values and preferences are important to consider when designing CRC screening programmes, although may be difficult to intervene on. The extent to which one should strive to modify individuals' values and preferences probably also depends on one's perspective, i.e., while it may be considered justified in order to increase screening participation, it may undermine the concept of SDM. The golden mean may thus be to acknowledge and organise the screening programme with consideration of the fact that individuals have different views as to what is important to them. For example, in this thesis, we do not know the extent to which our screening non-participants had turned down the offer of FIT testing or colonoscopy. However, there are other studies showing that combining these screening procedures, either sequentially with an initial invitation to colonoscopy followed by an invitation to FIT testing for those not responding or declining colonoscopy (111), or by offering individuals a choice (111, 112), can improve uptake. This is currently not part of the plan in the introduction of the Swedish national CRC screening programme, which will be based on FIT testing as the primary screening procedure, yet might be something to consider for the future. Also, including a values clarification exercise; e.g., ranking and rating attributes of importance and pros and cons of the screening when inviting individuals to participate in screening can help increase people's awareness of their values and preferences and thus improve decision quality (113), although it may not impact screening participation per se.

Irrespective of the decision made, most of our respondents made their screening decision without involving others. These results stand out from most other research within the field, in which, for example, involvement of healthcare professionals, such as a physician recommendation or a screening discussion, have been found to be important facilitators for screening uptake (67, 68). Still, they align with previous findings from the SCREESCO trial (46) and the Swedish breast cancer screening setting (75), and likewise from the CRC screening context in the Netherlands (110). Although one can only speculate, there is likely a multifactorial explanation to these results. This may, for example, include the design of the screening programme (organised vs. opportunistic) (67), cultural differences and similarities, i.e., where both Sweden and the Netherlands positions moderate to high in terms of individualism (114), and the Swedish healthcare tradition, in which people mainly seek and are offered healthcare for symptoms and not prevention. Nevertheless, from the perspective of SDM and Swedish legislation (39), it creates challenges for our healthcare sector as how to best support screening-eligible individuals in the decision-making process; i.e., how best to ensure that the greater part who may want to carry out the decision on their own can do so based on adequate knowledge and in line with their own values, and that those who prefer greater involvement of healthcare professionals have access to such support. For the latter, specially trained nurses could play an important role by, for example, offering telephone counselling. Such service was offered within the SCREESCO trial, which received a total of 10,000 calls during 2014–2020, and do also exists within the CRC screening programme in Stockholm–Gotland, where the helpline is open one hour every weekday.

In most of our study participants, regardless of whether they were screening participants or non-participants, the negative psychological impact of the screening was low, both in terms

of anxiety levels associated with the screening decision and worries along the screening pathway. This is important, considering the justification of CRC screening, as it is pivotal that screening programmes do as little harm as possible, which also applies to psychological consequences (28). However, there were some individual characteristics and certain moments or timepoints that were associated with experiencing greater anxiety or concerns. For minimising harms and facilitating the acceptance of screening, offering individuals the opportunity for psychological support should thus be a matter of course in the future CRC screening programme. Considering the psychological distress some individuals experience upon the receipt of an abnormal FIT result, it will also be important to research and review how such results are communicated. Within both the SCREESCO trial and the regional CRC screening programme in Stockholm–Gotland, abnormal FIT results are currently delivered by mail. However, the European guidelines for quality assurance in CRC screening recommend that abnormal screening results should ideally be communicated face-to-face, or at least by telephone, by a nurse or physician (28). Evidence regarding communication strategies for screening results and anxiety is, however, limited, and to the best of our knowledge, restricted to breast and cervical cancer screening settings with a lack of consensus (115).

It became obvious in this thesis that individuals experienced varying burdens as to the logistics of the FIT and colonoscopy. In line with previous research (76), FIT screening was mainly perceived as uncomplicated. However, given that some individuals found it demanding having to do the test twice, the procedure would likely benefit from the use of one-sample kits, as has been noted before (116). Furthermore, our and others' (80, 82) recognition of bowel preparation as the toughest part for many of those undergoing screening by colonoscopy, suggests that the overall acceptance of the procedure may improve by offering individuals a greater opportunity to choose among different laxatives as they can vary by both volume and taste (117). The most important finding within these results may, however, be that individuals' work- and life situations clearly affected how easy vs. difficult they had making time for their screening colonoscopy, and likewise, their access to sedation during the procedure. In this respect, individuals with limited ability to control their working hours appeared to be a particularly vulnerable group. This conflicts with updated Swedish legislation that strengthens the position of the individual and stresses accessibility and equity in healthcare (39). Thus, to provide care on equal terms in the context of screening, screening colonoscopies should be accessible during working hours without salary reduction. Such a regulation may also have a positive effect on the uptake of CRC screening, as screening non-participants in this thesis took into some consideration that the screening would be time consuming when choosing to decline.

8.2 DISCUSSION OF METHODS

As applies to all research, the studies undertaken this thesis have various strengths and limitations that should be taken into consideration when interpreting and reflecting upon the results.

8.2.1 Studies I-III

Being part of a sub-study to a large RCT like the SCREESCO trial brought many benefits to the studies in this thesis. One of the strengths is that we, unlike many other studies within the field, could rely on register-based data for screening participation and non-participation, and not on uptake based on self-report, which has been shown to have only moderate accuracy (118). This contributes to the studies' construct validity (99). Moreover, the SCREESCO trial was designed according to clinical practice and we could enrol a large number of individuals in the target age group for CRC screening, with various screening experiences, and from all over the country, including both urban and rural areas, which is a strength to both the statistical conclusion validity as well as the external validity of the results (99). However, a wider generalisation of the findings should be done with some caution as the response rate of screening non-participants was low, which is a common challenge in research involving individuals who do not participate in preventative healthcare services (119), still similar to or slightly higher than those of others (61, 120). Additionally, we did not perform any non-response analysis to compare those who responded to the online survey to those who did not. This was mainly due to lack of data to compare ours to, but also due to research ethics; i.e., we must always balance the likely benefits of our work against individuals' integrity and right to privacy (121). Thus, in this case, it was not considered ethically defensible to retrieve more information about non-responders and particularly not among those who had declined to take part in the screening. We do, however, know that our survey respondents display a similar distribution in education level and living situation as the general population of 60 year-olds when comparing with data from Statistics Sweden (122, 123). The proportion of women was, however, higher in our screening non-participant group.

Collecting data using online surveys is both convenient and cost-effective (124). However, there are some potential risks with this approach, such as technical issues and selection bias (124). To reduce those risks, our survey was pilot-tested and adjusted slightly before roll-out, and all individuals had access to technical support when responding. Consequently, the number of missing responses was consistently low throughout the studies, contributing to their power. To minimise the risk of excluding individuals with, for example, limited access to a computer, we also made it possible to respond to the online survey by telephone with support from one of the researchers. As for all survey research conducted in only one language, one can though not disregard the risk that there might be an underrepresentation of people with a foreign background among our respondents. The timing of the survey may also have induced a risk for recall bias.

The online survey consisted of a total of four questionnaires. When choosing and reflecting upon the results of questionnaires it is important to consider their psychometric properties; i.e., whether they are valid and reliable for the people under study (125). In the present thesis, both HL (Study **I**) and anxiety data (Study **II**) were collected using questionnaires that have been validated and confirmed reliable for the Swedish population (90, 126, 127); i.e., they measure the concept they intend to measure and do so with a high degree of consistency (125), which is a strength to the internal validity of the studies (128). Yet, in the psychometric evaluation of the S-FHL and S-CCHL scales the test group that was supposed to represent the general population turned out to be more homogenous than intended regarding gender and

level of education (i.e., a majority of highly educated women). Accordingly, the authors stressed the need for more validity tests for the scales to be applied to a broader population (126, 127). Within the coursework of this thesis, the HL scales were thus further assessed for construct validity in the current study population using exploratory factor analysis, demonstrating satisfactory results, i.e., the unidimensionality, of both scales (unpublished data). Additionally, the reliability of the STAI S-Anxiety scale was tested with a Cronbach's alpha, showing good internal consistency with a coefficient of 0.945 (Study **II**) (125). Concerning the SCREESCO questionnaire (Study **III**), that is still under development, findings of an initial Rasch analysis demonstrated several satisfactory results, yet also showed that the questionnaire in its current form has separation difficulties, such as with two of the subscales possibly measuring the same concept (95). As a result, the responses to the SCREESCO questionnaire were, in the present thesis, analysed and reported on an item level.

All statistical analyses were performed according to the manuals of each questionnaire and/or with respect to the basic assumptions of each statistical test, strengthening the statistical conclusion validity of the studies. However, the choice of dichotomising HL in Study **I** may have led to loss of information and be seen as somewhat insensitive as those with problematic HL skills were treated as having adequate HL in the analysis. Still, the methodological work of the study was done according to the manual and in close collaboration with one of the researchers who translated and culturally adapted the instrument to the Swedish context. Moreover, the purpose of the study was to distinguish those with inadequate HL, and it is questionable whether trichotmising the data would have been relevant. In addition, the results of the logistic regression analysis conducted to explore associations between higher anxiety levels related to screening decision and individuals' characteristics in Study **II** should be considered with the understanding that the independent variables included in the model only explained a low amount of the variation in anxiety levels (4.8–7.5%). Thus, there are likely other factors that have a greater bearing on whether individuals experience higher levels of anxiety related to their screening decision.

8.2.2 Studies I and IV

One way of ensuring and evaluating the trustworthiness of qualitative research is by considering the four criteria proposed by Lincoln and Guba: *credibility, dependability, confirmability* and *transferability* (99).

As previously mentioned, the SCREESCO trial constituted a major advantage for the recruitment of study participants in this thesis, both in terms of relevance and accessibility. For the qualitative part, the inclusion of individuals with various characteristics is a particular strength to the credibility of the studies, as it increases the likelihood of shedding light on the research questions from different angles (98, 125). The same applies to use of various methods for collecting data (i.e., FGDs and individual telephone interviews), although this was done primarily because of practical and ethical reasons.

The FGDs and individual telephone interviews were carried out by two experienced researchers with clinical backgrounds in gastroenterological nursing. Thus, they possessed

valuable qualities for establishing trusting relationships and posing relevant interview questions (99, 129), with the latter being further supported by the use of a semi-structured interview guide. Consequently, the generated data were rich, corresponded well to the purpose of each study, and were consistent throughout the data collection period, strengthening the credibility and dependability of the studies of concern (98, 99). However, the depth of the material varied, and especially for the individual telephone interviews, which is a limitation of the method that has been recognised by others (130). From such a perspective, it might had been valuable to conduct face-to-face interviews instead. Nonetheless, such a format could also have made it more difficult to recruit study participants and most certainly would have made it difficult to conduct interviews with individuals from various parts of the country, due to logistical barriers.

The FGDs and individual telephone interviews were audio-recorded and transcribed verbatim, contributing to the studies' confirmability (99). Data in both studies were analysed using inductive qualitative content analysis focusing on the manifest content of the transcripts. After coding, FGD- and individual telephone interview data were analysed together due to considerable similarities in overall content. It has been suggested that such analysis should be made with caution, as FGDs and individual interviews generate different types of data whose trustworthiness may be threatened if they are assumed to be equal (131). Taking this into consideration, efforts were made to keep track of which codes had been generated by which data collection method in Study **IV**. In the end, however, codes from both FGDs and individual telephone interviews were present in all subcategories, supporting our interpretation that the content was equivalent.

During the analytical processes, a peer debriefing technique was adopted to support the accuracy of how the data were interpreted, and thus, the confirmability of the studies (125). This was partly done through members of the research group analysing parts of the material independent of each other to verify the level of our agreement, but also through regular research group meetings in which the analytical steps and any possible preconceptions were reviewed, reflected on, and discussed. However, no member check was used to confirm the results of the analysis in either one of the studies, which could have been of value. To support the evaluation of the studies' credibility and confirmability (98), efforts have been made to illustrate the analytical process in the reporting of Study **IV** and to include representative quotations in both papers (Papers **I** and **IV**).

The findings of qualitative studies are not expected to be generalisable (129). However, they may be more or less transferable to other settings or groups. To help future readers evaluate the transferability of the present results, attempts have been made to include a rich description of the sample and the context in which the studies were conducted, though without putting confidentiality at risk (98).

9 CONCLUSIONS

This thesis adds to the understanding of factors and experiences associated with participation and non-participation in screening for CRC regarding HL, anxiety, aspects of SDM, and experiences of the screening procedure.

Most individuals, irrespective of whether they had participated in the screening or not had adequate HL, felt well informed but partially lacked knowledge of CRC and screening, did not involve any healthcare professional in decision-making, and experienced low levels of anxiety related to their decision. Screening participants and non-participants likewise described both pros and cons of the screening information materials, but differed in respect to their values and preferences by taking various matters into consideration when making the decision. Among those who undergone screening, various emotions and logistical issues appeared, with the most important probably being the influence of individuals' work- and life situation for colonoscopy experience.

Altogether, these findings indicate that there is room for improvement in the current communication and arrangement of CRC screening for facilitating high, informed, and equal participation among the Swedish population. Furthermore, they imply that individuals have various needs and may require different means of support throughout the screening process.

10 FUTURE RESEARCH

The results of this thesis can serve as a point of departure for future research initiatives on CRC screening participation and non-participation. Such work could include:

- interventions to support individuals in the decision-making process to make an informed and value-congruent decision regarding whether to participate in CRC screening. This work would likely benefit from a clearer description of what constitutes adequate knowledge and/or a discussion of whether we should measure the concept of being informed in terms of a one-size-fits-all or place greater emphasis on individual perceptions.

- exploring strategies to identify those individuals who may experience negative psychological impacts from CRC screening and ways of alleviating their concerns.

- a continued exploration of potential barriers to CRC screening, and reasons for why people choose not to participate. For this matter, subgroup analyses according to the type of screening procedure and individual characteristics could be of value.

- further addressing the issue of equity in CRC screening, by, for example, direct future research on screening participation and non-participation towards people with a foreign background and/or language barriers who are not commonly represented.

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