Fecal immunochemical test based colorectal cancer screening
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CHAPTER 11

Summary and future perspectives
The work reported in this thesis covers a wide range of issues, with most data collected in a second round of a screening pilot for colorectal cancer (CRC) in the Amsterdam region of the Netherlands. We started by reporting participation numbers and diagnostic yield, but we also spent a substantial effort on exploring the target population’s motivations, beliefs, feelings and experiences.

In chapter 2 we compared the yield of a second round of fecal immunochemical test (FIT)-based screening to that of a first round. We found an equal number of positive FITs in both rounds but the subsequent risk of finding an advanced adenoma or carcinoma at colonoscopy appeared to be significantly lower in second round positives. We concluded that in screening-naive persons, there seems to be a higher chance of finding a significant lesion following a positive test-result than in persons who had a positive test-result two years after a negative test-result. We did not observe a shift towards less advanced cancers stages.

In chapter 3 we looked at the participation rates and showed that overall a smaller proportion of invitees returned the FIT in the second round compared with the first round. When we looked in more detail at second round subgroups, we found that around 9 in 10 previous participants, 2 in 10 previous nonparticipants and 5 in 10 first-time invitees were willing to participate in the second round. Based on these findings we concluded that it seems worthwhile to reinvite persons who did not participate in previous rounds. A reason for concern was the uptake in the group of first-time invitees, which appeared to lag behind the average overall participation rate.

In chapter 4 we showed that supplying invitees with a collection paper to facilitate the stool collection process does not result in higher participation rates in a FIT-based screening program. Invitees randomly allocated to the group that did not receive a collection paper were equally willing to participate as persons who did. We concluded that the costs of supplying a collection paper with the FIT do not outweigh the benefits in terms of increasing participation rates.

In chapter 5 we reported the results of a questionnaire survey that evaluated reasons for engaging in FIT-based screening or not. Not surprisingly, an effort to learn more about the chance of getting cancer was by far the most frequently selected reason for participation. We were somewhat startled, however, to learn that one of the most common reasons given for refraining from participation was the absence of symptoms, which was picked by 3 out of 10 responding nonparticipants. In the implementation of a future screening program, effort should be put to adequately inform invitees that an absence of symptoms suggestive for CRC is not a legitimate reason to refrain from screening.

In chapter 6 we analyzed whether persons who had decided to accept the screening invitation had done so based on an informed choice. The vast majority of participants who had returned the questionnaire appeared to have sufficient knowledge about the screening program to enable informed decision making. Since 99% of them also had a positive attitude towards screening, 91% of decisions to participate could be qualified as informed. Unfortunately, we cannot draw conclusions on nonparticipants of the screening program, as the number of nonparticipants who returned the questionnaire was too small.

Chapter 7 reported the results of sending the Psychological Consequences of Screening Questionnaire to all invitees. We showed that screenees with a positive FIT result experienced
the largest level of distress shortly after having been informed about their positive test result. This distress gradually decreased after their visit to the outpatient clinic, where the meaning and implications of the test result were explained in a face-to-face conversation. Distress then decreased further at six weeks after having been informed about the results of their colonoscopy. This decrease was more pronounced in persons with a false-positive than in persons with a true-positive test result. Unfortunately, we cannot compare the scores in our screening population to a background population not invited for screening. We therefore do not know how these scores relate to the normal average-risk population.

In chapter 8 we reported the results of a small questionnaire survey among endoscopists and consecutive colonoscopy patients, which was carried out at the endoscopy unit of our teaching hospital. We showed that endoscopists do not necessarily agree with patients on what is important in the colonoscopy procedure. Endoscopists tended to overestimate the importance of adverse physical effects while they underestimated the importance of communication skills and involving patients in choices.

In chapter 9 we explored screenees’ experiences with colonoscopy as part of the complete screening procedure. We showed that persons with a positive FIT result perceived the bowel preparation and the postcolonoscopy abdominal complaints as the most burdensome aspect of the procedure. We also aimed at identifying aspects of the procedure that could be targeted in future efforts to improve the colonoscopy experience. Providing screenees with a good explanation of the procedure, discussing the preliminary colonoscopy results before they leave the hospital, and seeing to a short waiting time between learning the positive FIT result and the colonoscopy procedure could all add to a more satisfactory colonoscopy procedure.

Chapter 10 reports the results of a large multicenter trial that assessed non-screening patients’ experience with the colonoscopy, stratified by indication. This trial showed that the perception of the colonoscopy varied with the indication for which it was performed. Irritable bowel syndrome (IBS) patients and inflammatory bowel disease (IBD) patients experienced the largest burden. Different patient groups also attached different values to the procedure. IBD patients, for example, who often have had multiple colonoscopies in the past, reported a larger burden from the bowel preparation phase, while they were not very interested in the explanation of the procedure. We concluded that specific patient groups might benefit from a specific approach when offered a colonoscopy, one that is tailored to their needs and expectations.

At the time of the writing this summary, the Minister of Health has decided to initiate a nation-wide bowel cancer screening program using FIT. The program will start in September 2013. The research reported in this thesis indicates that we should try to pursue high informed-decision rates among all persons invited for screening, including hard-to-reach groups such as previous non-participants and ethnic minorities. We have shown that the majority of screening participants had made an informed choice to participate and that in the majority of cases they had done so because they wanted to gain more certainty about their chances of getting cancer. Unfortunately, we observed a disappointingly low questionnaire return rate among screening nonparticipants. Future studies should try to fill the void, by exploring alternative methods to study whether nonparticipation is also based on an informed decision, and to detect – and potentially remove – addressable barriers to participation.
Promising findings from our work on the diagnostic yield and participation of FIT-based CRC screening are the decreasing positive predictive value (PPV) for cancer and advanced adenomas over a repeated round, the continued participation of more than half of the population invited, and the re-uptake in previous nonparticipants. Somewhat less encouraging was the slightly lower overall participation in the second round, and the low participation rate among first-time invitees. We also failed to observe a significant shift towards less advanced cancer stages. The latter is not surprising as the efficacy of FIT-based CRC screening programs relies on an appropriate program sensitivity, which simply takes several rounds to establish. We have to await data from subsequent screening rounds to evaluate whether these trends are persistent.