Screening the CITY: optimizing population-based cancer screening in the Netherlands from a primary care perspective

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CHAPTER 2

Determinants of (non-)attendance at the Dutch cancer screening programmes: a systematic review

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Abstract

Objective

The Netherlands hosts three population-based cancer screening programmes (CSPs): for cervical, breast, and colorectal cancer. For a CSP to be effective high participation rates are essential. Current participation rates in the Netherlands are starting to fall below the minimal effective rate. This study aims to give a systematic overview of the current known determinants of (non-)attendance at the Dutch oncological screening programmes.

Methods

A comprehensive literature search was conducted in the electronic databases Academic Search Premier, Cochrane Libary, Embase, EMCare, PubMed, PsycINFO, Web of Science as well as in grey literature, including all articles published before February 2018. This study followed the PRIMSA guidelines. The I-Change model was used to categorise the identified determinants of screening attendance.

Results

In total 19/1232 identified studies were included, along with 6 grey literature reports. Fifteen studies reported on predisposing factors. Characteristics as social economic status, country of birth and residency are most often reported and correlate with screening attendance. Thirteen studies addressed information factors. Factors on awareness, motivation, ability, and barriers were less often studied.

Conclusion

Current studies tend to describe the general characteristics of (non-)attendance and (non-)attenders, but rarely provide in depth information on other factors of (non-) participation. The I-Change model proofed to be a useful tool in mapping current knowledge on cancer screening attendance and revealed knowledge gaps regarding determinants of (non-)participation at the CSPs. More research is needed to fully understand determinants of participation. This in order to influence and optimize attendance rates over the long term.

Introduction

The Netherlands invests considerable time and effort hosting three population-based cancer screening programmes (CSPs) aimed at cervical, breast, and colorectal cancer (CRC). CSPs aim to detect cancer in an early or precursor stage, thus improving survival via early intervention. On average, this approach is thought to lead to a better prognosis, as well as fewer and less severe side effects of the treatment.[1-4] CSPs in the Netherlands are offered free of charge by the Dutch government to all citizens of a specific age and gender. The National Institute for Public Health and the Environment (RIVM) and five regional screening organisations are charged with organizing and coordinating the programmes.[5] Attendance is voluntary and monitored yearly by the RIVM.[6-8] Although the three CSPs show many similarities, each CSP has its unique procedures and organization, mainly due to the differences in screening methods (Table 1). In Appendix A we describe the individual designs of the three CSPs.

High participation rates are essential for a national CSP to be effective. According to the World Health Organization (WHO) at least 70% of the target population should be screened.[9] Most recent national available attendance rates from the Netherlands (2016) were 60%, 77% and 73% for respectively the CSPs for cervical, breast and CRC. Despite these national numbers might be reassuring, an alarming sign is the downward trend in uptake which can be observed for both the long-lasting CSPs at cervical and breast cancer.[7,8,10] Furthermore, there is a wide regional variation in attendance rates; with the lowest attendance rates among the four largest cities of the Netherlands, which all fall below the 70%, the minimal effective rate, for all three CSPs.[11-13]

In order to influence and optimize attendance rates, it is essential to identify and understand determinants of (non-)attendance and follow-up adherence. This study aims to give a systematic overview of the current known determinants of (non-)attendance at the Dutch oncological screening programmes.

Table 1. Key characteristics of the three national cancer screening programmes in the Netherlands

		Cervical CSP	Breast CSP	Colorectal CSP
Since (year)		1979 (pilots from 1976)	1990 (pilots from 1984)	2014 (will be fully operational in 2019)
Population	Age category	30-60	50-75	55-75
	Sex	F	F	F&M
Interval (in years)		5	2	2
Primary test		hrHPV-test, cytology if necessary (then a Pap-smear as needed)	Mammography (bilateral)	FIT
Involvement GP		Performing cytological smear, discuss outcome, hospital referral[a]	Discuss outcome, hospital referral[b]	None[c]
Primary outcome		KOPAC-code[d]	BI-RADS-code	Negative, positive, unclear.
Financing	Invitation, primary test and analyses, referral when abnormalities are detected	Dutch government		
	Secondary tests & potential treatment	Standard healthcare, thereafter, depending on individual insurance policy		

F= Female, M= Male, hrHPV= high-risk Human papillomavirus, FIT= Faecal Immunochemical Test, GP= General Practitioner

[a]From 2017 onward, women can choose a self-sampling test. The outcome (negative, positive, or unclear) of the self-sampling test is not automatically shared with the GP, so the GP no longer plays an essential role in this CSP. If hrHVP is detected, women are advised to seek contact with their GP to perform a Pap smear at the GP's office.

[b]In cases where no abnormalities are detected the GP will not be involved.

[c]Since 2017 the GP no longer automatically receives the outcome of a FIT. However, after a positive FIT patients are encouraged to seek contact with their GP.

[d]KOPAC-code is a Dutch classification system comparable with the Pap-classification.

Methods

Search strategy

A comprehensive literature search was carried out which included all articles published before February 2018. We searched the following electronic databases: Academic Search Premier, Cochrane Library, Embase, EMCare, PubMed, PsycINFO, and Web of Science. The initial search was constructed in PubMed and included the following MESH terms: 'screening', 'cancer', 'participation' and 'Netherlands'. The full search is listed in Appendix B. The search was then extended to cover the other databases. No limitation was set on year of publication or study design. Grey literature was obtained from databases on the websites of the organizations RIVM,[5] Gezondheidsraad[14] and Volksgezondheidenzorg,[15] which are involved in cancer screening in the Netherlands. Reference lists of the included articles were reviewed for additional references. This review and its procedures were planned, conducted, and reported according to the PRISMA guidelines.[16] In advance our review was registered and accepted in the Prospero register of the National institute for Health Research (CRD42018089444).[17]

Study selection

Studies were included when they evaluated the outcome measurement "attendance/participation", and/or described the determinant measures "reasons for low and non-attendance" and were related to at least one of the current Dutch national CSPs. Studies were excluded when they were not in English or Dutch, or when they were non-original articles. Table 2 summarizes the inclusion and exclusion criteria. After removing duplicates, titles and abstracts were checked for inclusion and exclusion criteria. The abstracts of the remaining articles were independently assessed for applicability by the first and second author. The agreement rate was 92%, calculated over the first 120 articles (110/120). An additional 10% was randomly checked by the second author. In case of discrepancy the full text of an article was checked. The final full text evaluation of all the remaining articles was carried out by both the first and second author. Disagreement on inclusion was resolved by discussion with the full research team.

Table 2. Inclusion and exclusion criteria

	Inclusion criteria
1a.	Study outcome: the uptake/participation of national cancer screening programmes **OR**
1b.	Determinant measurements: reasons for low- and non-attendance (health literacy, decision making, social or cultural differences and organisational factors) AND cancer screening programmes
2.	Results are related to: cervical cancer and/or breast cancer and/or colorectal cancer
3.	The authors are related to Dutch organisations (universities) or the article describes Dutch cancer screening programmes
	Exclusion criteria
1.	Language other than English or Dutch
2.	Non-original articles, e.g. dissertations, reviews, case reports, editorials, oral presentations, poster presentations, book chapters

Quality assessment and data collection

All included scientific studies were subjected to qualitative analyses. For the quantitative studies the Crowe Critical Appraisal Tool (CCAT) was used.[18] For the qualitative studies we used the Consolidated criteria for reporting qualitative research (COREQ), as developed by the Dutch Cochrane Centre.[19] To analyse the determinants in a broad perspective, we used the Integrated Model for Behavioural Change (I-Change model, see Figure 1).

The I-Change model

Since screening attendance can be seen as health behaviour, determinants of this particular health behaviour can be studied by using health behaviour models. We used the Integrated Change model (I-Change model, Figure 1)[20-22] to map all the identified determinants. We chose this model since it incorporates elements from several earlier and highly used and appreciated health behaviour theories such as the Health Belief Model, Protection Motivation Theory, Theory of Planned Behaviour, and Precaution Adoption Process Model.[23-26] The I-Change model includes factors on predisposing, information, awareness, motivational, ability and barriers.

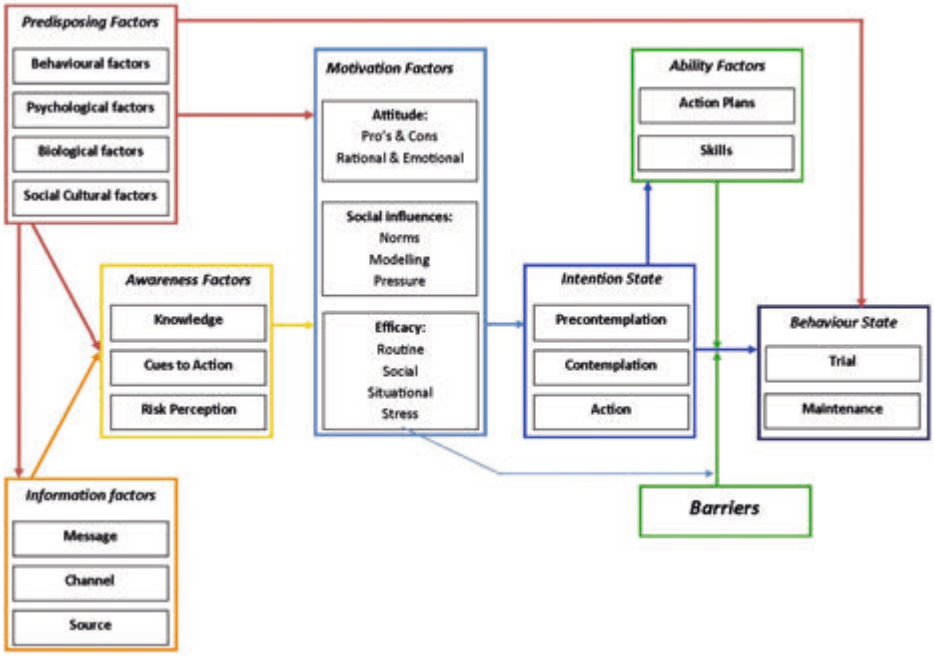

Figure 1. The Integrated Model for Behavioural Change (I-Change Model). The arrows represent the influence between the different factors

Results

Study retrieval

The initial search yielded a total of 2433 articles (Academic Search Premier 73, Cochrane Library 98, Embase 853, EMCare 185, PubMed 604, PsycINFO 23, Web of Science 597; see Figure 2 for the PRISMA flow chart). A total of 1201 articles were identified as duplicates and another 715 articles did not meet the inclusion criteria. Therefore, 517 studies remained after the first exclusion round. After the second round, 81 studies remained and were selected for full text review. In total 19 articles were included in the final selection, including 13 quantitative and 6 qualitative studies. The quality appraisal score of the 13 studies was average to high and ranged from 32 to 38 points (maximum 40), with a rounded average of 36 points. With respect to the qualitative studies, we scored a range from 5 to 6 (maximum 7) with a rounded average of 6 points. Since we did not assign extremely low-quality scores, we did not exclude any studies from further analysis based on the CCAT or the COREQ. Characteristics of the included studies are summarized in Supplementary Tables 1 and 2. Six reports were included as grey literature.[6,7,11,12,13,27] The identified determinants of low or (non-)attendance are presented in Table 3.

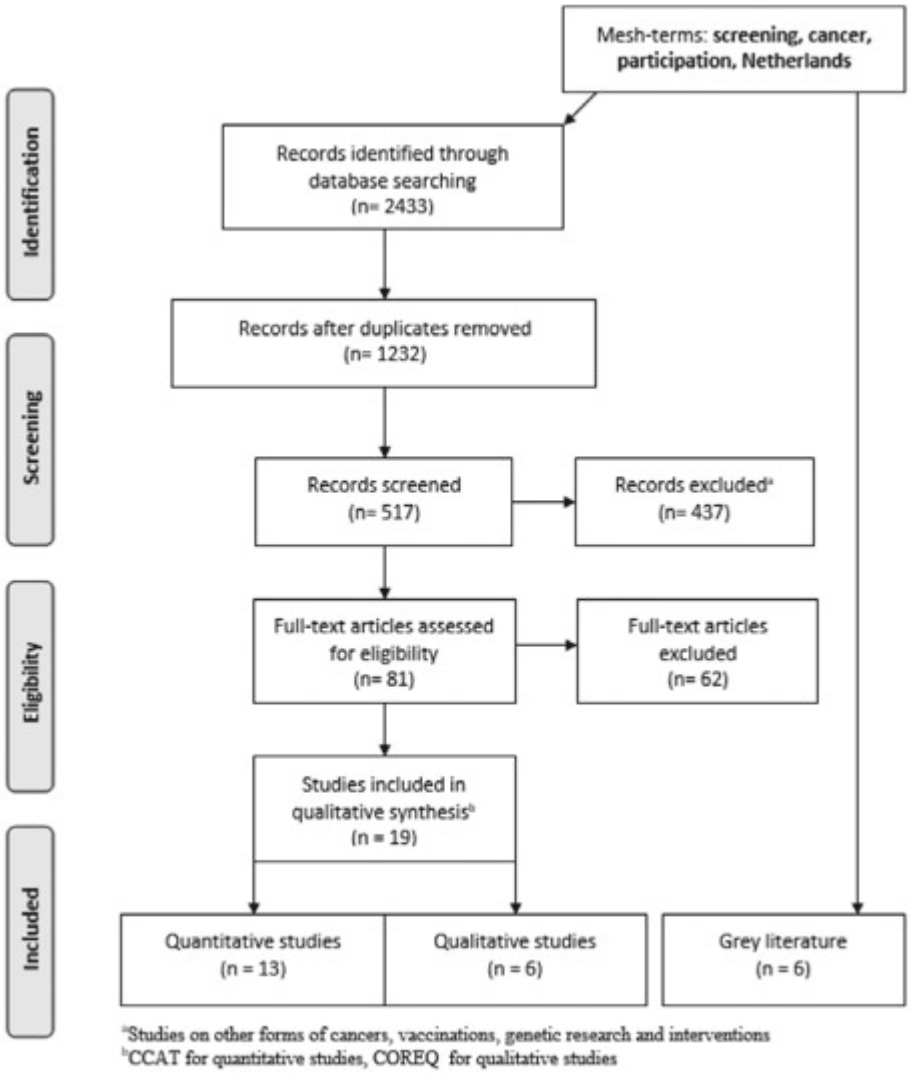

Figure 2. PRISMA flowchart of the search strategy. Search until 1st of February 2018

Predisposing factors

Most studies (n=15) reported on predisposing factors, mainly the general characteristics of (non)attenders.[6,7,11-13,28-37] For all three CSPs country of birth seems to influence attendance, with those not born in the Netherlands showing low(er) uptake.[12,28-33,36,37]

For the cervical and breast CSPs, residency and socio-economic status (SES) were frequently reported determinants of participation.[13,28,30,31,34-36] Women living in more

urbanized regions – the four main cities of the Netherlands: Amsterdam, Rotterdam, Utrecht and The Hague – and women belonging to a low-SES group showed lower attendance.[12,13,35] This is particularly detrimental as most abnormalities of the breast and cervix were found in women born outside the Netherlands and in women in lower SES-groups. Additionally, most unfavourable tumour-node-metastases were also found in the low-SES groups.[33,34,36-38]

Younger age was found to be a determinant of lower attendance in the cervical and the CRC CSPs,[6,7,11,31] whereas being single or divorced or having had only one sexual partner increases the likelihood of screening uptake in the cervical CSP.[28,31]

With respect to screening adherence and the implementation of the self-sampling test among non-responders, native Dutch non-attendees returned more of the self-sampling kits then non-native Dutch non-attenders. Furthermore, women who were screened in the previous rounds seemed to return more self-sampling kits than under-screened or never-screened women.[37]

Information factors

Thirteen studies described information factors to some extent.[29-32,35,38-45] At all three the CSPs several studies addressed the lack of tailored communication tools and strategies to inform subpopulations. The need to develop new tools and strategies has been recognized and would particularly benefit ethnic (minority) groups.[29,32,35,40,41,42,43]

Four studies related to the cervical CSP reported higher attendance rates when the invitation procedure (invitation and reminder) was general practitioner (GP)-based (the channel).[30,31,38,39] This approach was found to be particularly effective among women who were not born in the Netherlands.[30] The in 2017 introduced self-sampling test within the cervical CSP has been described as a promising, feasible and effective procedure for increasing coverage in a screening programme.[38,40,41] Self-sampling responders who did not participate in previous rounds were more often hrHPV positive and had a higher relative risk of ≥cervical intraepithelial neoplasia (CIN) II and ≥CIN III compared with self-sampling women who were screened in the previous rounds.[38,40]

Knops-Dullens et al. stated that in order to motivate Dutch women to participate in the screening programme they need to be convinced that the advantages outweigh the disadvantages.[44]

With respect to the CRC CPS a study adding extra instructions and information and addressing specific concerns should be considered in order to improve informed decision making about participation.[45]

Since January 2018 a GP no longer receives an automatically generated message in case of a pathological result, although patients are encouraged to seek contact with their GP.[27]

Awareness factors

Several studies identified the lack of knowledge as a determinant of non- or low-attendance.[31,37,42,46] Cervical CSP non-attenders felt that they had a lower risk of developing cervical cancer and were more convinced that cervical cancer cannot be cured.[31,40,44] A study among non-native Dutch found that all respondents recognized their susceptibility to CRC, but their knowledge of CRC and the CSP were limited.[42] Attending the CSP was a low priority, and limited concerns about health in general and serious concerns regarding safety were additional reasons for non- or low-attendance.[29,45,46] With respect to the cervical CSP, self-sampling might be a solution for non-attenders because of convenience and self-control.[29] Most often non-attenders reported they forgot to schedule an appointment.[29]

At the CRC CSP non-attenders thought that mainly individuals in poor health and with (cancer) symptoms would benefit from the programme. Knowledge of potential harm associated with CRC CSP was also low.[42]

Motivational factors

Non-attenders of the cervical CSP were less motivated, less often inclined to undergo future screening and experienced greater negative social influences. They reported negative role models and talked less with other people about the CSP.[44] Self-efficacy was identified as an important determinant for CRC CSP attendance.[42]

A positive remark could be found in the quick uptake and adherence of the CRC CSP. A study by Toes-Zoutendijk underlined the importance of real-time monitoring. Only a few months after implementation of the CRC CSP, participation and positive test results were higher than predicted, whereas the positive predictive value was lower than predicted. To reduce the burden of unnecessary colonoscopies and improve colonoscopy capacity, the cut-off level for a positive FIT result was adjusted and a cut-off level of 47µg Hb/g faeces is currently being used in the Netherlands.[43]

Ability factors

In the cervical CSP forgetting to make an appointment was the main reason for non-attendance.[29] The language barrier and low health literacy were other important determinants of non-attendance of the CRC CSP among non-native Dutch.[42]

Barriers

Non-attenders at both the cervical and the CRC CSP experienced more affective disadvantages: they were more insecure, more afraid, had more serious concerns regarding the test and outcome, and anticipated more feelings of shame. Other identified barriers were time-related or were related to being unable to attend the CSP, for example due to other illnesses.[29,44,45,46]

Concerning breast cancers, a study in 2011 stated that despite the absence of financial barriers for participation, SES inequalities in attendance rates existed.[34]

Table 3. Determinants of low-/non-attendance at a Dutch CSP, subdivided by the I-Change model

		Cervical CSP	Breast CSP	Colorectal CSP
Predisposing factors				
Behavioural	Residency: more urban	X[12]	X[13, 35]	
	Marital status: Married/in a relationship	X[28]		
	Several different sexual partners	X[31]		
Psychological				
Biological	Age: younger age	X[7,31]		X[6,11]
	Sex: male	NA	NA	X[8, 24]
	Higher risk (ethnicity)	X[36-38]	X[33,34]	
Social & Cultural	Country of birth: non-native Dutch/non-Western	X[12,28-31,36,37]	X[33]	X[32]
	SES: low(er) SES	X[28,30,31 36]	X[34, 35]	
Information factors				
Message		X[44]		X[45]
Channel	Lack of tailored strategies	X[29,40,41]	X[35,42]	X[32,43]
Source	Non-GP practice-based invitation	X[30,31,38,39]		
Awareness factors				
Knowledge	Misconceptions, lack of knowledge e.g. screening harm	X[31,37]		X[42,46]
Cues to action	Low priority	X[29]		X[45,46]
Risk Perception	Perceived lesser risk of cancer	X[31,40,44]		X[42]

Table 3. Determinants of low-/non-attendance at a Dutch CSP, subdivided by the I-Change model **(continued)**

		Cervical CSP	Breast CSP	Colorectal CSP
Motivational factors				
Attitude	No future testing needed, less moral obligation	X[44]		X[43]
Social influence	Negative social influence, negative role models, talked less with others	X[44]		
Self-efficacy	Low self-efficacy			X[42]
Ability factors				
Action plans	Forgot to make an appointment	X[29]		
Skills	Language barrier/low health literacy			X[42]
Barriers				
	Test: insecure, anxious	X[44]		X[45]
	Outcome of the test: insecure, anxious	X[44]		
	Inconvenience: feelings of shame	X[29, 44]		X[45]
	Time related: forgot, too busy	X[29]		X[46]
	Health related illness: other illnesses			X[46]
	Financial		X[34]	

CSP= Cancer Screening Programme, NA= Not Applicable, GP= General Practitioner

Discussion

This systematic review describes all known determinants of (non-)participation for the three Dutch cancer screening programmes (CSP). Studies tend to describe the more general characteristics of (non-)attenders, but rarely provide in depth information on other factors of (non-)participation. The I-Change model proofed to be a useful tool in mapping current knowledge on cancer screening attendance and revealed knowledge gaps regarding determinants of (non-)participation at the CSPs. Many studies reported on predisposing and information factors giving a general well understanding of these determinants. Factors on awareness, motivation, ability, and barriers were less often studied.

By using a theoretical framework designed to explain health behaviour, the I-Change model[47], we could systematically summarize and merge all information from the identified studies. Similar to other reviews, we were only able to take published literature into account, which could result into a publication bias. We choose for a health behaviour model since screening attendance can be seen as health behaviour. The I-Change model is a widely used and accepted theoretical framework to evaluate health behaviour.[20-22,48] The I-Change model states that behaviours are determined by a person's motivation or intention to carry out a behaviour, which is in turn the result of a person's intentions, abilities, and barriers. Attitudes, social influences, and self-efficacy expectations influence a person's motivation and are determined by various distal factors, such as predisposing (e.g., current lifestyle), information (e.g., source of delivery), and awareness (e.g. knowledge) factors. To the best of our knowledge this is the first review to use this approach to summarize available information on determinants of participation in CSPs. The I-Change model allowed us to identify knowledge gaps and so highlight opportunities for improvement.

For a CSP to be effective high participation rates are essential. The attendance rates for the two long-term CSP programmes in the Netherlands, cervical and breast cancer, are declining. The attendance rates of the cervical CSP are especially low and are below the 70% target which is seen by the WHO as the minimum effective rate. Furthermore, attendance rates show wide variation between regions and subpopulations. Lower attendance rates were found among those belonging to a low-SES group, living in more urban regions and among people who were not born in the Netherlands (in some studies referred to as 'non-native Dutch' and in others as 'non-Western immigrants'). These figures are in line with earlier published reviews.[49-51] Furthermore, younger women show lower attendance rates at the cervical CSP, and men in general show lower attendance

at the CRC CSP. The latter issue was also addressed in an earlier review on CRC CSPs worldwide by Navarro et al.[52]

While several studies have described attendance rates and the characteristics of (non-)attenders, in depth analyses of why people do or do not participate in a CSP are scarce. During our analysis it became clear that while many studies have focused on low attendance groups, little is still known on why these groups fail to attend CSPs and even less is known on why individuals from high attendance groups actually attend CSPs. When we considered various elements of the I-Change model, we were unable to find any studies on the sub-elements' psychological factors (predisposing factors) and message factors (information factors). With respect to the other (sub)elements of the I-Change model, most were only addressed in one study and/or in relation to only one CSP. One study by Hartman *et al*. attempted to interpret knowledge derived from research on the cervical CSP to explain factors concerning the breast CSP.[49] The sub-elements under the predisposing factors are most often reported as characteristics of the non-attenders.

As our focus was on Dutch CSPs, determinants of (non-)participation described in international studies of CSPs were excluded. Although several countries have comparable CSP to the Netherlands, every country has own and unique screening programs adapted to their health system and population. As these inter-nation-differences would cause a problem comparing results we choose to focus only the Netherlands. Some international reviews, however, have focussed on determinants not yet studied in the Netherlands, for example the sex of the screener, the presence of symptoms and the existence of family conflicts.[53-55] Additionally, lessons learned throughout this review might also be applicable to other European/Western countries.

In the Netherlands, the involvement of the general practitioner (GP) in the CSPs has decreased over the past five years. However, it is clear, at least for the cervical CSP, that direct involvement of the GP results in higher attendance rates, especially among the high-risk groups (high cancer risk in known low-attendance groups).[30,31,39] Whether this involvement should be (re)introduced is a matter of debate, but at the very least a more prominent GP role in informing and activating people to participate in CSPs could be further explored. The importance of such a role for GPs is highlighted in several international studies, with highest beneficial effects for the lower socioeconomic and minority groups.[56, 57]

It is often said that financial barriers are irrelevant in the Netherlands,[34] but this is only partly true. While participation in a CSP is free, whenever follow-up research is needed, a patient will have to cover a part of the cost of follow-up research themselves, depending

on their specific insurance plan. Since screening programmes may exacerbate socio-economic and ethnic health differences,[58] future studies are also needed that address this topic.

In this review we not only looked at the three Dutch CSPs individually, but also compared the outcomes of these CSPs. This allowed us to compare characteristics of non-attenders and determinants of participation. Of the three Dutch CSPs, cervical cancer screening shows the lowest attendance rates. In the literature some explanations were offered for why women often fail to attend the cervical CSP. However, a possible explanation for the low uptake might be that a cervical examination remains a greater taboo compared to examination of the breast. An additional explanation might be the concrete appointment arranged by the breast CSP, whereas in the cervical CSP women have to make an appointment with their GP themselves. An advantage of the CRC CSP compared to the cervical CSP is that the CRC faeces test can be completed at home. In 2017 a self-sampling test for HPV infection was introduced within the cervical CSP. The self-sampling test has shown to have high concordance with physician-taken sampling for hrHPV detection and was found to be highly acceptable to women.[59] It would be interesting to see the effect of this self-test on participation rates among the different cervical CSP attendance groups. While the self-sampling test appears promising, we think there is still room for improvement. Women are only informed about the possibility of a self-sampling test in the initial invitation letter from the screening organisation. An application form to actually order the self-sampling test is only attached when a re-invitation has to be sent. Therefore, women themselves still have to take the initiative in order to receive a self-sampling test at home. It would be more logical to include an application form with the initial invitation letter and to include the self-sampling test together with the re-invitation for women who have not yet responded to the first letter. A similar proposal has already (partly) been made by the Health Council of the Netherlands.[60] Besides the different tests used in the three Dutch CSPs, there are also clear differences in the occurrence of the different cancers. Per year 700-800 women are newly diagnosed with cervical cancer, whereas the incidence of breast and CRC is far higher at 16.000 and 13.000 cases per year, respectively. A higher incidence means that people are more likely to be aware of breast and CRC, or to know someone who has had breast or CRC compared to cervical cancer.

In conclusion, although the three CSPs in the Netherlands generally have high attendance rates, large differences are present between different regions and subpopulations. The I-Change model highlighted many knowledge gaps in determinants of (non-)participation and identified opportunities for improvement. Current studies tend to focus on attendances rates and the general characteristics of (non-)attenders, but rarely provide in depth information on determinants of (non-)participation. We therefore feel that more

detailed studies are needed, as only by understanding the determinants of participation can we influence and alter them, and thus optimize current CSPs over the long term.

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Appendix

A. Description of the three Dutch national cancer screening programmes

Cervical cancer screening programme

The cervical CSP was nationally implemented in 1979 and currently invites women aged between 30-60 years to participate at 5-year intervals.[1, 2] Over the past few years several adjustments have been made to the design of this CSP.[3] In 2016 the invitation strategy was altered; whereas potential participants used to be invited by their own GP or by the local screening organization, nowadays this is the exclusive responsibility of the local screening organization. In 2017 adjustments were made regarding the testing procedure and the time interval of the cervical CSP. First, instead of performing a classical Papanicolaou (Pap) smear for cytological abnormalities at the GP's office, a new test for high-risk human papilloma virus (hrHPV) was added prior to investigation of aberrant cells. Several studies have shown that adding an HPV test is both more sensitive and specific in the detection of cervical cancer than cytology alone.[4-6] A second modification was the introduction of the self-sampling test for hrHPV. Before 2017 all women who wanted to participate had to see their GP for a smear, whereas they can now choose to use the self-sampling test instead. However, if this test gives a positive result, they still need to see their GP in order to have a smear that can be checked for cytological abnormalities. The outcome of the hrHPV test is sent by letter by the local screening organization. In case of a positive cytological result, hospital referral will be handled via the GP. A final change, also implemented in 2017, is an adjustment to the length of the interval between individual tests. Women aged between 45 and 55 only receive an invitation if they tested positive in previous rounds or did not attend. The maximum screening interval can therefore be extended by 10 years for women from the age of 40.

Breast cancer screening programme

The breast CSP became nationally available in 1990.[7] All women aged between 50 and 75 years (till 1998 age boundaries were 50-70 years) are biennially invited by letter, via a local screening organization, for a mammography. Women are able to refuse participation by unsubscribing from the invitation letters, either temporarily or for all future invitations. Most mammography's take place at mobile research units, where two independent radiologists assess the mammogram (double reading). The results are shared with the participants via the screening organizations. In case of an unclear outcome of a mammogram or when a disorder is detected, further investigation will be needed, and the GP will be informed. The GP will contact the participant and arrange a hospital referral. Women are informed about the outcome by letter via the screening organization, which also provides information on the subsequent follow-up.[8]

Colorectal cancer screening programme

The CSP for colorectal cancer (CRC) is relatively new (2014) and the entire programme should be fully implemented by 2019.[9] Invitation depends on year of birth, and both men and women aged between 55-75 years are invited. Invitees can choose to unsubscribe from participation. In case of no response a reminder is sent after two months. If a re-invitation remains without response, the potential participant will only be re-invited after an interval of two years.[10] The faecal immunochemical test (FIT) was chosen as screening test, since previous studies found this test to be the most acceptable to the Dutch population.[11] This test can easily be performed at home. FIT screening requires successive screening rounds for optimal programme sensitivity.[11] The cut off level for a positive FIT was increased in mid-2014 from 15 to 47µg Hb/g faeces. This was done in order to reduce the burden of unnecessary colonoscopies and improve colonoscopy capacity. Referral is arranged by the local screening organization.[12] The GP has no active role within this CSP, but patients are advised to seek contact with their GP after a positive FIT.[13]

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B. Mesh terms and free text search. As used for the initial search in PubMed

('Mass Screening'[Mesh] OR 'Mass Screening'[All fields] OR 'Mass Screenings'[All fields] OR 'cancer screening'[All fields] OR 'cancer screening programme'[All fields] OR 'Screening programme'[All fields] OR 'population screening'[All fields] OR 'screening programmes'[All fields] OR 'national population screening'[All fields] OR 'cancer screening programs'[All fields] OR 'screening programs'[All fields] OR 'Early Detection of Cancer'[Mesh] OR 'Early Detection of Cancer'[All fields] OR 'screening'[all fields]) AND ('Breast Neoplasms'[Mesh] OR 'Breast Neoplasms'[All fields] OR 'Breast neoplasm'[All fields] OR 'Breast cancer'[All fields] OR 'Breast cancers'[All fields] OR 'Mammary cancer'[All fields] OR 'Mammary cancers'[All fields] OR 'Breast carcinoma'[All fields] OR 'Breast carcinomas'[All fields] OR Colorectal*[all fields] OR 'colon'[all fields] OR 'Colorectal Neoplasms'[Mesh] OR 'Colorectal Neoplasms'[All fields] OR 'colorectal neoplasm'[All fields] OR 'colorectal carcinoma'[All fields] OR 'Colorectal Carcinomas'[All fields] OR 'Colorectal tumor'[All fields] OR 'Colorectal tumors'[All fields] OR 'colorectal cancer'[All fields] OR 'colorectal cancers'[All fields] OR 'colorectal adenomas'[all fields] OR 'colorectal cancer screening'[all fields] OR 'uterine'[all fields] OR 'uterus'[all fields] OR 'cervix'[all fields] OR 'cervical'[all fields] OR 'Uterine Cervical Neoplasms'[Mesh] OR 'Uterine Cervical Neoplasms'[All fields] OR 'Cervix cancer'[All fields] OR 'cervix cancers'[All fields] OR 'cervix neoplasm'[All fields] OR 'cervix neoplasms'[All fields] OR 'cervical neoplasms'[All fields] OR 'cervical neoplasm'[All fields] OR 'cervix carcinoma'[All fields] OR 'cervical cancer'[All fields] OR 'cervical carcinoma'[All fields] OR 'Neoplasms'[Mesh] OR 'Neoplasms'[All fields] OR 'neoplasm'[All fields] OR 'cancer'[All fields] OR 'cancers'[All fields] OR 'carcinoma'[All fields] OR 'carcinomas'[All fields] OR 'tumor'[All fields] OR 'tumors'[All fields] OR 'cancer screening'[all fields]) AND ('Netherlands'[Mesh] OR 'Netherlands'[all fields] OR 'Netherlands'[ad] OR 'Holland'[tw] OR 'Dutch'[All fields] OR 'hague'[tw]) AND ('No-Show Patients'[Mesh] OR Non attend*[all fields] OR nonattend*[all fields] OR 'Non attending patients'[All fields] OR 'No Show patient'[All fields] OR 'No Show patients'[All fields] OR No-Show*[all fields] OR noshow*[all fields] OR 'uptake'[All fields] OR 'participate'[All fields] OR 'participation'[All fields] OR 'patient participation'[Mesh] OR 'Patient participation'[All fields] OR 'screening uptake'[All fields] OR 'attending'[All fields] OR 'attendance'[All fields] OR 'Mass Screening/utilization'[Mesh] OR 'Patient Dropouts'[Mesh] OR Dropout*[all fields] OR drop out*[all fields] OR dropped out*[all fields] OR 'Patient Compliance'[Mesh] OR 'compliance'[all fields] OR compliant*[all fields] OR comply*[all fields] OR 'utilization' [Subheading] OR 'Utilization Review'[Mesh] OR utilisation*[all fields] OR utilization*[all fields] OR 'Patient Acceptance of Health Care'[Mesh]

Supplementary Table 1. Characteristics of the included quantitative studies, per type of cancer screening programme

Cervical cancer screening programme

Reference	Study design	Number of participants (n)	Participants, collection period, region	Characteristics	Outcomes	I-Change model
(Gok, Heideman et al. 2012) **Ref: 38**	Retrospective observational cohort study	54,482 non-responders Group 1: 27,792 (self-sampling group 1) & 281 (recall/control group). Group 2: 26,145 (self-sampling group 2) & 264 (recall/control group).	Women, age 30-60. Between December 2006 to March 2008. North Holland and Flevoland. Non-responder= Women who had not responded to two invitations from the regular screening programme in 2005 & 2006. Self-sampling tool per group: 1: Delphi-Screener 2: VibaBrush	Age (group) Screening history Method invitation Country of birth Self-sampling: 29% Recall: 12% Group 1: 27% Group 2: 31%	Native Dutch non-attendees responded better than immigrants (32% vs. 22%, p<0.001) and those screened in previous round revealed higher response than underscreened or never screened. ≥ CINII rates were higher amongst responding native Dutch women than immigrants (p<0.001), and higher in under-/never- screened women than in women screened in the previous round (p<0.001). Self-sampling increases efficacy screening programme by targeting a substantial portion of non-attendees of all ethnic groups who have not regularly been screened and are at highest risk of ≥CIN II.	Predisposing factors Awareness factors

Cervical cancer screening programme (continued)

Reference	Study design	Number of participants (n)	Participants, collection period, region	Characteristics	Outcomes	I-Change model
(Gok, Heideman et al. 2010) **Ref: 37**	Prospective observational cohort study	28,073 non-responders 27,792 were assigned to self-sampling group & 281 to the recall group/ control group.	Women, age 30-60. Between December 2006 to December 2007. North Holland and Flevoland. Non-responder = Women who had not responded to two invitations from the regular screening programme.	Age Screening history Self-sampling group 26.6% vs. 16.4% of the control group.	Self-sampling responders who did not participate in the previous rounds of screening had an increased relative risk of ≥CIN II and ≥CIN III compared to self-sampling women who had been screened in the previous rounds. Self-sampling is a feasible and effective method for increasing coverage in a screening programme. Especially because of the higher risk in non-attenders.	Predisposing factors Information factors

Cervical cancer screening programme (continued)

Reference	Study design	Number of participants (n)	Participants, collection period, region	Characteristics	Outcomes	I-Change model
(Bais, Van Kemenade et al. 2007) **Ref: 40**	Interventional trial in addition to the regular population-based cervical cancer screening programme	2,830 non-responders 2,546 were assigned to the self-sampling group & 284 to the recall group/control group.	Women, age 30-50. Between January 2003 and April 2004. North Holland. Non-responder = Women who had not responded to two invitations from the regular screening programme. Control group received second re-invitation.	Age Screening history Self-sampling 34.2% vs. 17.6% of the control group.	hrHPV positive self-sampling responders were less likely to have a prior screening history than screening participants. Self-sampling is attractive adjunct to increase uptake, without markedly increased costs.	Information factors

Cervical cancer screening programme (continued)

Reference	Study design	Number of participants (n)	Participants, collection period, region	Characteristics	Outcomes	I-Change model
(Bulkmans, Bulk et al. 2006) **Ref: 41**	Retrospective observational cohort study hrHPV testing was added to cervical screening in the POBASCAM-trial.	44,102	Women, age 30-60. Between 1999-2002. Amsterdam (North Holland).	Before: 58.7% and after: 61.4% implementation hrHPV testing.	hrHPV testing can be added to cervical screening by cytology without a decrease in participation rate.	Information factors
(Van Leeuwen, De Nooijer et al. 2005) **Ref: 36**	Retrospective observational cohort study	251,446	Women, age 30-60. Between 1998 and 2001. South Holland & Zeeland.	Age SES Country of birth Overall: 55.7% Born in the Netherlands: 56.8% Other Western countries: 45.3% Moroccan: 35.9% Turkey: 48.0% Suriname: 51.3% Dutch Antilles: 46%	Although cervical screening is free of charge, participation rates differ greatly between ethnic groups and between women from different socio-economic strata. Abnormalities were found more often in women who were not born in The Netherlands and in women with lower socio-economic status. These groups show lower attendance at the screening programme.	Predisposing factors

Cervical cancer screening programme (continued)

Reference	Study design	Number of participants (n)	Participants, collection period, region	Characteristics	Outcomes	I-Change model
(De Nooijer, De Waart et al. 2005) **Ref: 30**	Retrospective observational cohort study	237,719 37.1% by invitation of the GP and 62.9% by Municipal Health Service (GGD).	Women, age 30-60. Between 2000-2003. South Holland & Zeeland.	Age SES Country of birth Invitation Zip code After GP invitation 7.9% higher attendance than by GGD.	After invitation by a GP attendance rates were 7.9% higher for the entire population. This difference was even higher for women born in Morocco, Turkey, Suriname and the Dutch Antilles and for women with low-SES and living in a rural area.	Information factors

Cervical cancer screening programme (continued)

Reference	Study design	Number of participants (n)	Participants, collection period, region	Characteristics	Outcomes	I-Change model
(Hermens, Tacken et al. 2000) **Ref: 39**	Cross-sectional observational study	5,548 Selection of 122 family practices, representative of all family practices in The Netherlands. Approximately 40 practices per approach. Evaluation of three organizational approaches. Comparison between family practice-based, community-based, and a combination of the two.	Women, age 35-60. Between September and November 1996. The Netherlands.	Age Invitation strategy Younger women (≤45): Family practice-based approach: 68% Combination approach: 62% Community-based approach 53% Older women (>45): Family practice-based approach: 58% Combination approach: 60% Community-based approach 47%	A reminder from the family physician increased the attendance rate from 7 to 11%. A family practice-based cervical screening approach appeared to be the most effective at a national level, achieving the highest attendance rate (also highest coverage and control rate).	Information factors

Cervical cancer screening programme (continued)

Reference	Study design	Number of participants (n)	Participants, collection period, region	Characteristics	Outcomes	I-Change model
(Kreuger, van Oers et al. 1999) **Ref: 28**	Retrospective observational cohort study	70,621	Women, aged 35-54, between 1992 and 1994. In 53 neighbourhoods of Rotterdam (South Holland).	SES Marital status Nationality Range: 36-58%, depending on neighbourhood.	Risk groups are clustered in neighbourhoods and can be identified by SES, marital status and nationality. High-SES level of a neighbourhood, low-percentage migrants, single or divorced women correspond with high attendances.	Predisposing factors

Breast cancer screening programme

Reference	Study design	Number of participants (n)	Participants, collection period, region	Characteristics	Outcomes	I-Change model
(Aarts, Voogd et al. 2011) **Ref: 34**	Retrospective observational cohort study	1,067,952	Women, age 50-75, from 1998 to 2006. Southern Netherlands Data combined with the Eindhoven Cancer Registry (ECR). As of 1998 women aged 70-75 were also invited within this screening programme. Before 1998 age boundaries were 50-70.	Age SES Year of invitation Low-SES: 79% Medium-SES: 85% High-SES: 87%	Women with low-SES had an unfavourable tumour-node-metastasis. Despite the absence of financial barriers for participation, SES inequalities in attendance rates exist.	Predisposing factors Barriers

Reference	Study design	Number of participants (n)	Participants, collection period, region	Characteristics	Outcomes	I-Change model
(Vermeer and Van Den Muijsenbergh 2010) **Ref: 35**	Retrospective observational cohort study	977,961 (1997-1998) vs. 1,279,982 (2007-2008)	Women, 50-75 year. Comparison between attendance rates of 1997-1998 and 2007-2008. The Netherlands.	Country of birth Invitation period Screening region Attendance rates 1997-1998: Dutch: 81% Africa, Asia or Latin America: 56% Turkish: 50% Moroccan: 43% Attendance rates 2007-2008: Dutch: 83% Africa, Asia or Latin America: 63% Turkish: 62% Moroccan: 54%	The Western region, where most migrants live, had the lowest attendance rates in 1997-1998 and in 2007-2008. Attendance rates of migrant women increased over the past 10 years. However, specific efforts to increase the attendance rates are needed because current attendance rates are still far below the overall rates.	Predisposing factors Information factors

Reference	Study design	Number of participants (n)	Participants, collection period, region	Characteristics	Outcomes	I-Change model
(Visser, van Peppen et al. 2005) **Ref: 33**	Retrospective observational cohort study	824,916	Women, age 50-75 between 1995 and December 2002. North Holland & Flevoland. Data on invited and/ or screened women in a second or subsequent round. As of 1998 women aged 70-75 were also invited within this screening programme. Before 1998 age boundaries were 50-70.	Age Area of residence Country of birth Overall attendance: 76% Residents of Amsterdam: 68% Attendance rate per country of birth: Netherlands 79% Suriname 59% Turkey 44% Morocco 37%	Women born in non-Western countries attend breast cancer screening less frequently, but also have a low detection rate. This justifies a passive attitude towards the low attendance.	Predisposing factors

Colorectal cancer screening programme

Reference	Study design	Number of participants (n)	Participants, collection period, region	Characteristics	Outcomes	I-Change model
(Toes-Zoutendijk, van Leerdam et al. 2017) **Ref: 43**	Retrospective observational cohort study Monitoring of the newly nationally enrolled cancer screening programme.	741,941	Target population 2014. Males and females reaching age of 63, 65, 57 or 75 years. The Netherlands.	Sex Age 71.3%	A few months into the program it appeared that participation and positive test results were higher than predicted. The positive predictive value was lower than predicted. To reduce the burden of unnecessary colonoscopies and improve colonoscopy capacity, the cut off level for a positive FIT was increased. Close monitoring of the implementation of the program allowed for rapid adjustment.	Information factors Motivational factors

Reference	Study design	Number of participants (n)	Participants, collection period, region	Characteristics	Outcomes	I-Change model
(Deutekom, Rijn et al. 2009) **Ref: 32**	Prospective observational cohort study	10,054	Males and females, age 50-75. Between May 2006 and January 2007. Amsterdam (North Holland). Study was performed before the implementation of the national screening programme. Invitations by Comprehensive Cancer Centre Amsterdam (CCCA).	Age Sex Country of birth Overall: 49%. Dutch: 52% Other Western: 46% Suriname and Antilles: 36% Asian: 38% Middle East and Central East: 21% African: 34%	Participation among ethnic minority groups was significantly lower than among ethnic Dutch. Studies are needed to explore whether groups are not reached or that lower uptake is determined by other causes.	Predisposing factors Information factors

Supplementary Table 2. Characteristics of the included qualitative studies, per type of cancer screening programme

Cervical cancer screening programme

Reference	Study design	Number of participants (n)	Participants, collection period, region	Characteristics	Outcomes	I-Change model
(Bosgraaf, Ketelaars et al. 2014) **Ref: 29**	Questionnaire study	30,130 (non-responders). Analysis of 9,484 with self-sampling device and 682 without.	Women, age 30-60. Between October 2011 to December 2012. North Holland, Flevoland, Utrecht & Gelderland.	Non-attendance: forgot to schedule an appointment. The main reason to use the self-sampling device: own time-setting. Convenience and self-control. 30.9% who did not use self-sampling device preferred after all to have a cervical smear taken instead.	Organisational barriers are the main reason for non-attendance of regular cervical screening. Self-sampling might be a solution for non-attenders because of convenience and self-control.	Information factors Barriers
(Knops-Dullens, de Vries et al. 2007) **Ref: 44**	A computer-assisted telephone survey	165 100 attendees and 65 non-attendees. Random sample of 300 attendees and 600 non-attendees. Drawn from a total of 20,000 women.	Women, age 30-60. Between January and July 2001. Limburg.	Attendees perceived more positive social influence, more positive role models, talked more often with others and perceived a more positive norm. Non-attendees experienced more affective disadvantages, were more insecure and afraid of smear taking, experienced more feelings of shame and were more insecure and anxious about the result.	In order to motivate Dutch women to participate in the screening programme they need to be convinced that the advantages outweigh the disadvantages.	Information factors Awareness factors Barriers

Reference	Study design	Number of participants (n)	Participants, collection period, region	Characteristics	Outcomes	I-Change model
(Tacken, Braspenning et al. 2007) **Ref: 31**	Questionnaire study	Analyses on 1392 women (968 screened and 424 unscreened). 2,224 (1204 screened, 1020 unscreened).	Women, age 30-60. Between December 2000 and February 2001. The Netherlands.	Women aged 40-50 years who felt a high personal moral obligation, who had only ever had one sexual partner, and who were invited and reminded by their own general practice had the greatest likelihood of screening uptake. Women's beliefs are the best predictors of uptake. Non-responders (mainly unscreened) thought they had less risk of cervical cancer, were less motivated, less often intended to take part in future screening, and were more convinced that cervical cancer cannot be cured.	To improve uptake: focus on moral obligation of eligible women, beliefs about the risk of cervical cancer, and available cures. Invitations and reminders within general practices enhance the uptake rate.	Predisposing factors Information factors Motivational factors

Colorectal cancer screening programme

Reference	Study design	Number of participants (n)	Participants, collection period, region	Characteristics	Outcomes	I-Change model
(Woudstra, Dekker et al. 2016) **Ref: 42**	Qualitative interviews (purposive sampling)	30	First-generation immigrants age 48-74. (born in Turkey, Morocco and Suriname). Between February-July 2014. Amsterdam (North Holland)	All respondents felt susceptible to CRC. Knowledge about screening harm and self-efficacy to participate was low. Adult children acted as important mediators. The language and low literacy formed serious barriers to informed participation.	To ensure equal opportunities for informed participation in screening, target strategies should be developed, such as oral and visual, and face-to-face communication in the mother tongue. This will help minority groups in informed decision making in CRC screening.	Information factors Awareness factors Ability factors
(Hummel, Steuten et al. 2013) **Ref: 46**	Web-based questionnaire	167	Target population screening programme, age 55-75. April 2011. Choice between: iFOBT, colonoscopy, sigmoidoscopy, and CT colonography. The Netherlands.	Most preferred was CT colonography. Screening test with highest intention to attend was the iFOBT.	While respondents may recognize the importance of diagnostic effectiveness in the long term, their short-term decision to attend the screening tests may be less driven by this consideration. Inconvenience, safety and frequency of tests are the strongest technique-related determinants of the respondents' intention to participate in colorectal screening programs.	Awareness factors Barriers

Reference	Study design	Number of participants (n)	Participants, collection period, region	Characteristics	Outcomes	I-Change model
(Van Rijn, Van Rossum et al. 2008) **Ref: 45**	Standardized telephone interviews	312 non-participants analysed. Random selection of 500 people out of the non-responders of a cohort of 20,623 people who received an invitation for faecal occult blood test.	Non-participants of the faecal occult blood test, age 50-75. Between November 2006 to May 2007. The Netherlands.	Most reported reasons for non-participation were: time- or priority- related. Other reasons were health-related issues.	Main reasons not to participate reflect low priority. This was associated with a lack of knowledge. Adding extra instructions and information and addressing specific concerns should be considered in order to improve informed decision making about participation.	Information factors Awareness factors Barriers

PRISMA 2009 Checklist			
Section/topic	**#**	**Checklist item**	**Reported on page #**
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	3
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	3
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	4
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	4
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	4

(continued)

PRISMA 2009 Checklist			
Section/topic	**#**	**Checklist item**	**Reported on page #**
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	17
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	4
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	4
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	4
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	4/5
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	Table 3
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	-
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	4

(continued)

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	-
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	5, Figure 2
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Sup. Table 1/2
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	5
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Table 3
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	-
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	5
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	-
DISCUSSION			

(continued)

PRISMA 2009 Checklist			
Section/topic	**#**	**Checklist item**	**Reported on page #**
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	7
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	8-10
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	10
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	1

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097
For more information, visit**: www.prisma-statement.org**.

Dubbelpublicatie Huisarts en Wetenschap

Waarom mensen niet deelnemen aan oncologische bevolkingsonderzoeken

Thom Bongaerts, Frederike Büchner, Barend Middelkoop, Onno Guicherit, Mattijs Numans

Oncologische bevolkingsonderzoeken zijn op populatieniveau alleen effectief als een groot deel van de doelgroep eraan meedoet. Nederland kent 3 van dergelijke bevolkingsonderzoeken: naar baarmoederhals-, borst- en darmkanker. Zorgelijk is dat de huidige opkomstcijfers van die onderzoeken een dalende trend laten zien en soms al onder de effectieve grens liggen. Wij hebben de achtergronden van (niet-) deelname in kaart gebracht. Huisartsen kunnen mogelijk een belangrijke rol spelen bij het keren van de dalende trend.

Dit is een bewerkte vertaling van Bongaerts THG, Büchner FL, Middelkoop BJC, Guicherit OR, Numans ME. Determinants of (non-)attendance at the Dutch cancer screening programmes: a systematic review. J Med Screen 2019:969141319887996.

Momenteel zijn er in Nederland 3 oncologische bevolkingsonderzoeken (bvo's): de screeningprogramma's naar baarmoederhals- (BMHK), borst- (BK) en darmkanker (DK). Het idee achter deze bvo's is dat wanneer de specifieke kanker in een vroeg stadium wordt opgespoord, zowel de behandeling als de prognose verbetert. Deel- name is vrijwillig en het primaire screeningsonderzoek is gratis. Potentiële deelnemers worden uitgenodigd op basis van de combinatie van leeftijd en geslacht. Het Rijksinstituut voor Volksgezondheid en Milieu (RIVM) en 5 lokale screeningsorganisaties zijn verantwoordelijk voor de organisatie en coördinatie van deze programma's. De rol van de huisarts is in elk bvo anders en aan verandering onderhevig.

De Wereldgezondheidsorganisatie berekende dat ten minste 70% van de doelpopulatie gescreend moet worden, wil een nationaal screeningsprogramma op populatieniveau effectief zijn.[1] In 2018 lag de deelnamegraad op 57,6%, 76,6% en 73% voor respectievelijk de bvo's naar BMHK, BK en DK. De opkomst bij het bvo-BMHK is dus te laag en de opkomstcijfers van zowel het bvo-BMHK als het bvo-BK laten de afgelopen jaren een dalende trend zien.[2] In de 4 grote steden zijn de opkomstcijfers van alle 3 bvo's lager dan de effectieve grens van 70%.[3,4] Deze cijfers geven daarmee reden tot zorg. Hoewel de oproepen zijn gericht aan (delen van) de algemene populatie, lijkt het er ook op dat

de opkomst ongelijk verdeeld is naar medische risico's en naar sociaal-economische achtergrond. De bvo's kunnen daarom wellicht baat hebben bij een klinische, proactieve en wijkgerichte benadering vanuit de 1e lijn.

Om de huidige opkomstcijfers te begrijpen is het noodzakelijk om een duidelijk beeld te krijgen van de achtergrond van (niet-)deelname en de daarmee gepaard gaande, wellicht beïnvloedbare factoren. Ons onderzoek had als doel om systematisch in kaart te brengen welke determinanten van (niet-)deelname aan de Nederlandse bvo's reeds onderzocht zijn.

Methode

We deden een systematisch literatuuronderzoek waarin we alle artikelen meenamen die voor februari 2018 zijn gepubliceerd. Daarvoor doorzochten we databases Academic Search Premier, Cochrane Library, Embase, EMCare, PubMed, PsycINFO en Web of Science. De initiële zoekstrategie voerden we in PubMed uit met de MESH-termen 'screening', 'cancer', 'participation' en 'Netherlands'. Ook grijze literatuur namen we mee; deze betrof vooral artikelen van het RIVM en de lokale screeningsorganisaties.

Voorafgaand aan de zoekopdracht hebben we de procedure beschreven en geregistreerd.[5] Na het verwijderen van alle duplicaten includeerden we artikelen wanneer deze voldeden aan de volgende inclusiecriteria:

1a. Onderzoeksuitkomst: deelname aan een oncologisch bevolkingsonderzoek; OF
1b. Determinanten: redenen voor lage/niet-deelname EN oncologisch bevolkingsonderzoek;
2. Resultaten gelinkt aan baarmoederhals-, borst- of darm- kanker;
3. Auteurs gelieerd aan Nederlandse organisaties OF het artikel beschrijft een Nederlands oncologisch bevolkings- onderzoek;
4. Beschikbaar in het Engels OF Nederlands;
5. Alleen origineel onderzoek.

WAT IS BEKEND?

- Nederland telt 3 oncologische bevolkingsonderzoeken (bvo's).
- Wil een bevolkingsonderzoek effectief zijn, dan moet de opkomst per bvo ≥ 70% zijn.
- De huidige opkomstcijfers laten een dalende trend zien en geven daarmee reden tot zorg.

WAT IS NIEUW?

- Onbeïnvloedbare determinanten als geboorteland, woonplaats en sociaal-economische status worden het vaakst beschreven in relatie tot deelname aan een bvo.
- De huidige onderzoeken beschrijven slechts zelden meer gedetailleerde informatie over alle, eventueel wél beïnvloedbare factoren van (niet-) deelname.
- De huisarts kan de screeningsdeelname mogelijk positief beïnvloeden. Waarschijnlijk hebben de van oudsher moeilijk bereikbare groepen hier het meeste baat bij.

De 1e en 2e auteur screenden de artikelen op titel en abstract. Wanneer er verschil van mening was over de inclusie van een bepaald artikel bespraken we dit met het hele onderzoeks- team. Voorafgaand aan de definitieve inclusie onderwierpen we de onderzoeken aan een kwaliteitsanalyse. Voor het analyseren van de determinanten gebruikten we het Integrated Model for Behavioural Change (I-Change-model; [**figuur]**). Dit is een gezondheidsgedragsmodel dat is opgebouwd uit eerdere en veelgebruikte modellen uit de gezond- heidspsychologie.[6] We gebruikten dit model omdat screeningsdeelname gezien kan worden als gezondheidsgedrag. Het model beschrijft gedrag dat wordt bepaald door onderliggende motivaties en intenties. De mate van de motivatie is afhankelijk van 3 factoren: attitude, sociale invloed en zelfeffectiviteit. Deze motivatiefactoren worden weer beïnvloed door andere factoren, zoals predispositie-, informatie- en awareness-facto- ren (zie verderop).

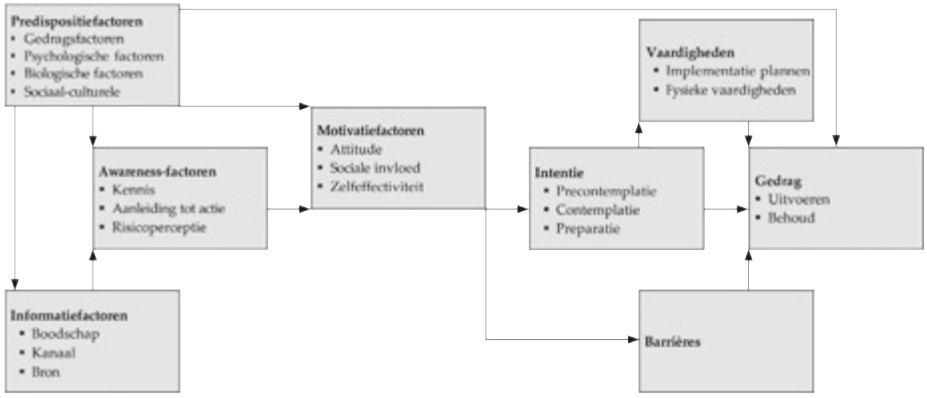
Resultaten

De initiële zoekopdracht leverde 2433 artikelen op. Bijna de helft (n = 1201) betrof duplicaten en 715 artikelen voldeden niet aan de inclusiecriteria. In totaal onderwierpen we 81 artikelen aan een tekstuele beoordeling, waarna we uiteinde- lijk 13 kwantitatieve en 6 kwalitatieve publicaties overhielden. De kwaliteitsanalyse leidde niet tot exclusie van artikelen. De **[tabel]** geeft een samenvatting van alle gevonden determinanten voor lage/niet-deelname.

Predispositiefactoren

Vijftien artikelen beschreven predispositiefactoren. Bij alle bvo's blijkt het geboorteland gerelateerd aan deelname: een geboorteland buiten Nederland correleert met een lagere deelname. Voor het bvo-BMHK en -BK worden woonplaats en sociaal- economische status (SES) als determinanten beschreven. Vrouwen woonachtig in stedelijke gebieden

(Amsterdam, Rotterdam, Den Haag en Utrecht) en/of behorend tot lagere SES-groepen participeren daarbij minder frequent. Een jongere leeftijd hangt bij het bvo-BMHK en -DK samen met een lagere deelname. Vrouwen die getrouwd zijn of een vaste partner hebben nemen eveneens minder vaak deel. Uit de literatuur over de nieuwe zelfafnametest voor het bvo-BMHK blijkt dat vrouwen geboren in Nederland vaker een set terugstuurde dan vrouwen geboren buiten Nederland. Vrouwen die eerder hadden deelgenomen blijken ook meer mee te doen aan vervolgonderzoeken. Onze zoekstrategie leverde geen artikelen op die psychologische factoren beschrijven in relatie tot de screeningsdeelname.



Figuur. Het Integrated Model for Behavioural Change (I-Change model).[6] De pijlen staan voor de onderlinge invloed tussen de verschillende factoren.

Tabel. Determinanten van lage/niet-deelname, onderverdeeld op basis van het I-Change-model.

			Bvo	
		BMHK*	**BK***	**DK***
Predispositiefactoren				
Gedragsfactoren	Burgerlijke staat: getrouwd/vaste partner	1		
	Verschillende seksuele partners	1		
Psychologische factoren				
Biologische factoren	Leeftijd: jongere leeftijd	1		2
	Geslacht: mannelijk	n.v.t.	n.v.t.	2
	Hoger risico (etniciteit): niet-Nederlands/niet-Westers	3	2	

Tabel. Determinanten van lage/niet-deelname, onderverdeeld op basis van het I-Change-model. **(continued)**

		Bvo		
		BMHK*	**BK***	**DK***
Sociaal-culturele factoren	Geboorteplaats: niet-Nederlands/niet-Westers	7	1	1
	Woonplaats: meer stedelijk	1	1	
	SES: lagere SES	4	2	
Informatiefactoren				
Boodschap	Niet overtuigend, niet mogelijk voor- en nadelen tegen elkaar af te wegen	1		1
Kanaal	Gebrek aan op maat gemaakte strategieën	3	2	2
Bron	Uitnodiging niet door de huisarts	4		
Awareness-factoren				
Kennis	Misvattingen: gebrek aan kennis	2		2
Aanleiding tot actie	Lage prioriteit toekennen	1		2
Risicoperceptie	Gevoel minder risico te lopen	3		1
Motivatiefactoren				
Attitude	Geen vervolgonderzoek noodzakelijk, minder een morele verplichting	1		1
Sociale invloed	Negatieve sociale invloeden, negatieve rolmodellen, nauwelijks gespreksonderwerp	1		
Zelfeffectiviteit	Lage zelfeffectiviteit			1
Vaardigheden				
Implementatie plannen	Vergeten een afspraak te maken	1		
Fysieke vaardigheden	Taalbarrière/lage gezondheidsvaardigheden			1
Barrières				
	Onderzoeksmethode: onzeker, angstig	1		1
	Onderzoeksuitkomst: onzeker, angstig	1		
	Ongemak: gevoelens van schaamte	2		1
	Tijdgerelateerd: vergeten, te druk	1		1
	Gezondheidsgerelateerd: andere ziekten			1
	Financiën: geen geld voor deelname aan vervolgonderzoek		1	

Bvo = oncologisch bevolkingsonderzoek, BMHK = baarmoederhalskanker, BK = borstkanker, DK = darmkanker, SES = sociaaleconomische status. * = aantal gevonden artikelen per determinant per bvo.

Voor het bvo-BMHK en -BK worden woonplaats en sociaal- economische status (SES) als determinanten beschreven. Vrouwen woonachtig in stedelijke gebieden (Amsterdam, Rotterdam, Den Haag en Utrecht) en/of behorend tot lagere SES-groepen participeren daarbij minder frequent. Een jongere leeftijd hangt bij het bvo-BMHK en -DK samen met een lagere deelname. Vrouwen die getrouwd zijn of een vaste partner hebben nemen eveneens minder vaak deel. Uit de literatuur over de nieuwe zelfafnametest voor het bvo-BMHK blijkt dat vrouwen geboren in Nederland vaker een set terugstuurde dan vrouwen geboren buiten Nederland. Vrouwen die eerder hadden deelgenomen blijken ook meer mee te doen aan vervolgonderzoeken. Onze zoekstrategie leverde geen artikelen op die psychologische factoren beschrijven in relatie tot de screeningsdeelname.

Informatiefactoren

Dertien artikelen beschreven informatiefactoren. De bestaan- de informatie blijkt niet altijd overtuigend genoeg. Velen vinden het lastig om een goede afweging over deelname te maken. Momenteel is er een gebrek aan op maat gemaakte communicatiemiddelen en -strategieën. Dit lijkt vooral problematisch voor de van oudsher moeilijk bereikbare groepen, die tevens het kwetsbaarst zijn (ze hebben vaker afwijkingen in ongunstigere stadia).

In het verleden vonden selectie en uitnodiging voor het bvo-BMHK plaats vanuit de huisartsenpraktijk. Nadat deze procedure was veranderd, viel de deelname terug. De hoge- re deelname voor de verandering betrof vooral de moeilijk bereikbare vrouwen: niet geboren in Nederland, behorend tot een lagere SES-groep en woonachtig in de stad.

Awareness-factoren

Het gebrek aan kennis over de specifieke soorten kanker en de bijbehorende bvo's is beschreven als determinant voor niet-deelname. Over het algemeen lijken niet-deelnemers sneller te denken dat ze geen/minder risico lopen, waarbij ze ervan uitgaan dat de betreffende vorm van kanker niet te genezen is.

Ook blijkt deelname aan een bvo vaak als laag urgent te worden ingeschat. Enkele artikelen beschrijven de zorgen over (test)veiligheid (en daarmee de weerstand) die potentiële deelnemers hebben.

Motivatiefactoren

Niet-deelnemers rapporteerden vaker negatieve rolmodellen (onder anderen de huisarts), bij wie deelname nauwelijks een gespreksonderwerp vormde.

Vaardigheden
Aan het bvo-BMHK werd vooral niet deelgenomen omdat potentiële deelnemers vergaten om een afspraak te maken. Lage gezondheidsvaardigheden werden het meest gerapporteerd bij het bvo-DK.

Barrières
In de literatuur werden ook problemen beschreven met het begrijpen van de Nederlandse taal en tijdgerelateerde barrières. Voor het bvo-DK gold dat deelnemers weinig vertrouwen hadden in de testprocedure zelf.

Beschouwing

We hebben gekeken welke determinanten voor deelname aan de 3 Nederlandse bvo's er in de literatuur te vinden zijn. Factoren als geboorteland, woonplaats en SES worden het vaakst genoemd. Dit soort determinanten is moeilijk te beïnvloeden. We vonden nauwelijks literatuur met gedetailleerdere informatie en over eventueel wél beïnvloedbare factoren van (niet-) deelname. Toch lijken er voor huisartsen mogelijkheden te bestaan om de screeningsdeelname te beïnvloeden en daarmee de oncologische screening op een zinvolle manier onderdeel te maken van een klinische, proactieve en wijk- of populatiegerichte aanpak.

Uniek aan dit onderzoek is het gebruik van het I-Change-mo- del. Dit theoretische kader stelde ons in staat om alle beschikbare informatie systematisch te achterhalen en te categoriseren. Daarnaast konden we de bvo's onderling met elkaar vergelijken. Zo bleek bijvoorbeeld dat het bvo-BMHK het meest onderzocht is en dat dit bvo de laagste deelnamegraad kent. Hiervoor is (nog) geen eenduidige verklaring gevonden. Misschien is deelname aan het bvo-BMHK voor veel mensen nog steeds taboe. Een mogelijke andere verklaring is dat er voor het bvo-BK een concrete afspraak volgt, terwijl vrouwen voor het bvo-BMHK zelf een afspraak moeten maken. Onder andere daarom is in 2017 de zelfafnametest geïntroduceerd. We hebben ons onderzoek nadrukkelijk niet gericht op buitenlandse bvo's en de daar reeds onderzochte factoren die invloed hebben op de screeningsdeelname. Dat deden we omdat de opzet van de bvo per land verschilt. Dat neemt niet weg dat onderzoek naar buitenlandse bvo's ook nuttige kennis kan opleveren.

De afgelopen jaren is de rol van huisartsen bij de preventie van ziekten veelvuldig besproken.[7] Als gevolg hiervan is hun aandeel bij de bvo's steeds kleiner geworden. Zo worden ze bijvoorbeeld sinds januari 2018 niet meer automatisch op de hoogte gebracht van de uitslag van het bvo-DK.8 Als huis- artsen weer een prominentere rol zouden krijgen, kan dat de informatie-, awareness- en motivatiefactoren, en daarmee

de screeningsdeelname, positief beïnvloeden. Dat is van belang omdat vroege opsporing en signalering van dit soort ziekten ook in de huisartsenpraktijk klinische consequenties hebben. Te denken valt aan een meer effectieve, proactieve, gestructureerde, populatie- en risicogroep gerichte inzet van de huisarts. In het verleden is gebleken dat juist de van oudsher moeilijk bereikbare groepen, die vaak ook de kwetsbaarste mensen betreffen, baat hebben bij een centrale en actieve rol van de huisarts. De persoonlijke en continue wijkgerichte en gezinsgeneeskundige zorg die de huisarts biedt lijkt hierbij van essentieel belang. Zo'n prominente en proactieve benadering past de huisarts en is klinisch relevant.

Toekomstig onderzoek zou het inzicht in de determinanten van screeningsdeelname nog verder moeten vergroten, zodat een veel gerichter stimulerend beleid kan worden vormgegeven. Daarnaast zouden we zowel het onderzoek naar optimalisering van de rol van de huisarts binnen de bvo's, als de discussie hierover willen stimuleren.

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