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

Bongaerts, T.H.G.

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CHAPTER 1

General introduction

Cancer is a heterogenic group of diseases characterized by uncontrolled growth of abnormal cells with the potential to invade surrounding tissue or spread throughout the body.¹ Each type has its own causes, symptoms, and specific treatment.² Worldwide, cancer is a major and growing health problem, and one of the leading causes of death.³ The increase of cancer cases can be largely attributed to the aging and growing population, as well as to current and persisting lifestyle habits.⁴ Recent numbers show that worldwide one in five men (20%), and one in six women (17%) will get cancer at some point in their lives. Approximately one in eight men (13%), and one in 11 women (9%) who develop cancer, will also die as a result of the disease.⁵ Many people around the world will thus encounter cancer (directly or indirectly). According to the World Health Organization (WHO) between 30% and 50% of the cancer cases can be avoided through the effective implementation of prevention strategies.⁶

Currently in the Netherlands, more than 120,000 people are diagnosed with cancer each year (incidence) and about 600,000 people live with a cancer diagnosis (prevalence).^{7,8} Since both the incidence and prevalence are expected to further increase in the upcoming years, it is not surprising that cancer also plays an important role in primary care, and in general practice (GP)- practices.^{9,10} Not only are GPs involved in recognising early symptoms and diagnosing the disease, they are also involved in the guidance of cancer patients during and after treatment. The Dutch College of General Practitioners (NHG; Nederlands Huisartsen Genootschap) stated that GPs have an increasingly important role to ensure continuous and person-centred care with respect to the care for cancer patients.¹¹ Per standard practice (around 2500 patients) a GP is encountered by an average of 25 new adult patients with (different types of) cancer per year, which equals one new patient per two weeks.¹² During the course of their disease, these patients require substantial high levels of care and support. The future increase of patients will therefore also lead to a further increase of the cancer related activities for GPs and GP-practices.

Cancer screening

Since cancer requires time to develop, cancer screening can be used as an important tool for reducing the cancer related burden and mortality worldwide. Cancer screening aims to detect a specific cancer in an early or precursor stage, when symptoms are minimal, chances of recovery are highest, and less intense treatment options with fewer side effects are often available. Therefore, most developed countries have established some form of cancer screening. In Europe and other Western-countries, screening is most often offered in the context of a population-based cancer screening programme (CSP).¹³ As cancer is a heterogenic disease, not all types of cancer are suitable for screening. Already

in 1968, Wilson and Jungner established specific criteria to help determine whether a certain disease is eligible for screening.¹⁴ These criteria include that the disease must be an important health problem, there must be an effective treatment available, the natural history of the disease must be well understood, the test must be suitable for mass application, and the outcome of the screening programme (SP) should be monitored and evaluated. The WHO added a couple of extra criteria in 2008, regarding: the availability of diagnostic and treatment services, a suitable infrastructure, acceptability to the population, and several ethical and social issues.¹⁵ One of these ethical criteria states that the benefits of screening should outweigh the potential disadvantages of the screening. As this appears to be rather complicated to determine, there is a strong and ongoing debate on the effectiveness of the CSPs.¹⁶⁻¹⁹ While proponents indicate that cancer-specific mortality is decreasing, critics indicate that it has changed little or nothing in absolute mortality within screened populations.^{20,21} In general, most people do have a rather positive attitude towards the CSPs, and in the current literature there seems to be consensus that current (European) CSPs lead to a better prognosis, as well as to fewer and less severe side effects of the treatment(s).²²⁻²⁴ Consequently, most European countries have implemented population wide CSPs aiming at early diagnosis of cervical, breast, and colorectal cancer.²⁵ In order for a screening programme (SP) to be successful the amount of attenders – i.e. the attendance rates – must be adequately high and should be evaluated.²⁶⁻²⁸ Modelling studies aimed to predict the effect on cancer mortality of CSPs were found to be highly dependent on the attendance rates.^{26,29} According to the WHO at least 70% of a target population, without further pre-selection, should be screened in order for a CSP to be effective on population level.^{4,30,31}

Cancer screening in the Netherlands

The Netherlands currently hosts three centrally organized population-based cancer screening programmes (CSPs) aiming at cervical, breast, and colorectal cancer. These CSPs 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; Rijksinstituut voor Volksgezondheid en Milieu), and the national screening organisation (Bevolkingsonderzoek Nederland) are in charge of organizing and coordination these programmes.^{32,33} The Netherlands has a strict law on population screening (Wbo; Wet op het Bevolkingsonderzoek), which has been in place since 1996.³⁴ Attendance is voluntary and monitored yearly by RIVM.³⁵⁻³⁷ Although all three CSPs show many similarities, each CSP has its unique procedures and organization, mainly due to differences in screening methods and recruitment system (Table 1).

Table 1. Key characteristics of the current CSPs in the Netherlands

	Cervical CSP	Breast CSP	Colorectal CSP
Available since (year)	1979 (pilots from 1976)	1990 (pilots from 1984)	2014 (fully operational since 2019)
Population			
Age boundaries	30-60	50-75	55-75
Sex	F	F	F + M
Interval (years)	5	2	2
Screening test	HPV-test, if HPV positive then cytology (Pap-smear)	Mammography (bilateral)	FIT
GP involvement	Performing Pap-smear, discuss outcome, hospital referral ^b	Discuss outcome, hospital referral ^b	None ^c ; discuss outcome
Screening outcome	HPV absent, present or unclear (re-testing). When applicable Pap-classification and HPV-typology	Abnormality absent (BI-RADS 1-3), abnormality present (BI-RADS 4-5), not enough information (BI-RADS 0)	Negative (no examination needed), positive (examination needed), unclear (re-testing)
Financing			
Invitation, screening test(s) and analyse	Dutch government		
Secondary test(s) and treatment		Standard healthcare, hence depending on one's individual insurance policy	

CSP= Cancer Screening Programme, F= Female, M= Male, HPV= Human Papillomavirus, GP= General Practitioner, FIT= Faecal Immunochemical Test

^a From 2017 onward, women can opt to receive a self-sampling test (after being invited). The outcome of the self-sampling test is not automatically shared with the GP due to privacy legislation. Outcomes will only be shared with the GP, if it is explicitly stated that the GP is allowed to receive this information. Hence, the GP no longer plays an essential role in this CSP. If HPV is detected, women are recommended to contact their GP to have a smear test taken at the GP-practice.

^b In cases no abnormalities are detected, the GP will not be involved.

^c Since 2017 the GP no longer automatically receives the outcome of a FIT. Outcomes will only be shared with the GP if it is explicitly stated that the GP is allowed to receive this information. After a positive FIT patients are encouraged to seek contact with their GP. When a patient visits the GP, he/she can provide an overview of a patient's medical record, which the colonoscopy centre could ask for.

General practitioner involvement in cancer screening

As already briefly described, general practitioners (GPs) are involved in the current cancer screening programmes (CSPs) in the Netherlands and have certain ‘formal’ tasks. This involvement is however limited, varies between the programmes and has changed over time. GPs are relatively closely involved with the screening programme (SP) aiming at cervical cancer. Mostly they perform the Pap-smear, discuss the outcome, and refer the patient to the gynaecologist if necessary. Since 2017 procedures changed, and women have the option of using a self-sampling test. When women opt for this, the outcome of the self-sampling test is not automatically shared with the GP, due to privacy legislations. Outcomes will only be shared with the GP, if it is explicitly stated that the GP is allowed to receive this information. Regarding the CSP on breast cancer, the GP is involved in discussing the outcomes with participating women if abnormalities are detected (BI-RADS 4-5), or if insufficient clarity could be obtained (BI-RADS 0), and also arranges the referrals to the hospital when indicated. As for the colorectal CSP, the GP is the least involved. The GP will only discuss the outcomes with the patient upon request, and subsequently provides an overview of the patient’s medical record for intake at the colonoscopy centre when indicated (Table 1).

In addition to these ‘formal’ tasks, GPs also have certain other, less strict defined tasks, such as explaining the pros and cons of participating in the CSPs when patients ask for that, and/or following requests for the guidance of patients who received outcomes of the screening test(s).³⁸⁻⁴¹

Regardless of the specific role GPs have regarding the CSPs, GPs will always have a vested interest in well-organized and effective operating CSPs, as they will be the first health professionals to notice the effects when they are not functioning properly.

Challenges in current cancer screening

Current Dutch cancer screening programmes (CSPs) face numerous challenges, of which several concern the uptake of screening participation. Both nationally and regionally, the average attendance rates of the CSP targeting cervical cancer have become insufficient already for a decade. In addition, at a national level, the attendance rates for all three CSPs have declined over the past years (Figure 1). Whereas the latest percentages for the three CSPs (2022) were 54.8%, 72.5%, and 70.6%, for the programmes aiming at cervical, breast and colorectal (CRC) respectively, the attendance rates in 2010, for the cervical and breast CSPs, were still 65.5% and 80.7% respectively.³⁵⁻³⁷ Since the CRC-SP has only been fully operational since 2019 (in all age groups), it is too early to

draw any conclusions on longer trends regarding this screening programme (SP). In this context, it should be noted that in literature, the CRC-SP is considered a success story; despite its recent introduction, it already achieved decent screening participation rates. Furthermore, at the regional level, there is a wide variation in screening participation rates, with lowest screening uptake among the four largest cities of the Netherlands, all way below the minimal intended effective rate of 70%, as stated by the WHO, for all three CSPs.³² Moreover, there is a growing belief among GPs working in the large cities – the highly urbanised areas – of the Netherlands, that the people who could potentially benefit most from participating in screening are the least likely to participate. These screening participation challenges are not unique to the Netherlands, as they also occur in other similar countries, such as the Scandinavian countries, the United Kingdom and Australia.⁴²⁻⁴⁵

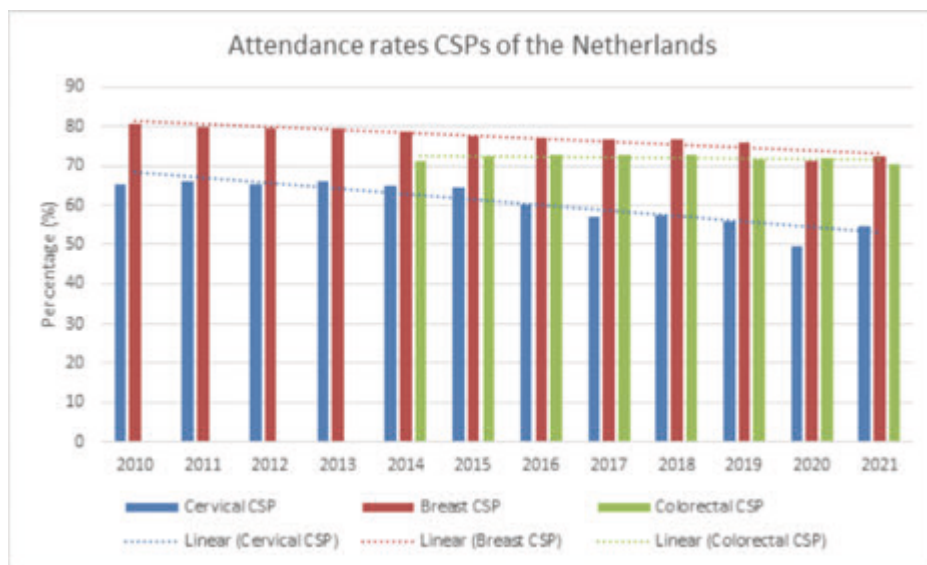


Figure 1. Attendance rates between 2010 and 2021. Based on the yearly monitoring reports of RIVM. The horizontal grey line at 70% indicates the minimal effective rate as stated by the WHO. CSP= Cancer Screening Programme

Besides the challenges related to screening participation, there are other challenges related to both screening-eligible people and GPs. Issues which will be discussed in this thesis, are illustrated by the case of the Janssen family.

The story of the Janssens family – The Questions

The Janssen family lives in a big city in the Western part of the Netherlands. The family consists of three members: Maria, the mother, 54 years old; John, the father, 59 years old; and their daughter Sarah, 30 years old. They all see their general practitioner (GP) because they have questions concerning the cancer screening programmes (CSPs). Sarah just recently received an invitation to participate in the CSP aiming at cervical cancer. Maria and John recently had a discussion on participating in the colorectal cancer (CRC) screening programme (SP).

When Sarah consults the GP, she indicates that she does not know whether she wants to participate in the SP. She has read several stories on the internet, including that it has to do with changing sexual partners. Sarah just had one and the same boyfriend for many years now. Sarah tells the GP, that her mother Maria said to not act so weird and that she should 'just participate'. Maria's argumentation is: "The CSPs are very important and for a serious cause, so why not just participate?". Sarah does agree that the programmes are for a serious case, but also wonders about the disadvantages of participating. Thereby she read something about the self-sampling test, but she doubts that she is able to perform it herself.

When Maria gets invited for one of the CSPs, she always faithfully participates. She does think the CSPs are a bit of a hassle, but afterwards she is always relieved when nothing abnormal is found.

When Maria and John visit the GP, John mentions that he recently received an invitation (he might have overlooked an earlier invitation) to participate in the CSP on CRC. He indicates that he does not understand what he has to do with the stool test, and in addition, he says he was very surprised that he was suddenly invited. He thinks it is really strange that he actually never heard about the CSPs before.

The GP answers the family's questions as best as possible, but after the consultations he starts thinking on the advises and about the CSPs in general. Does Sarah have a point that it does not actually make sense for her to participate in the SP? What are actually the benefits and harms of participating in CSPs? Is it still best practice for everyone to always participate, thinking about Maria? Or is there any evidence why people are sometimes better off not participating? And what about John. Would there be many people who do not understand the invitation and have no idea about the CSPs at all? Finally, what is actually his role as a GP regarding the CSPs? Are the programmes organised efficient and effective, and as a GP, should he actually have a role in the CSPs?

Objective and outline of this thesis

The overall aim of this thesis was to identify cues that might contribute to optimizing the current attendance rates of the cancer screening programmes (CSPs) in the Netherlands, with a focus on the potential role of primary care. We explicitly use the term ‘optimize’, as it was not our intention to conduct studies with the main aim of increasing screening attendance. The presented studies in this thesis have the overarching goal to identify ways to screen screening-eligible people at highest risk, i.e., people who are a priori most likely to develop (one of) the screening-specific tumours. We stated our hypothesis as follows: where current CSPs handle a ‘one-size-fits-all’ approach, with a limited role for primary care and GPs, it may be more beneficial, also with respect to the sustainability of the CSPs, to shift to a more targeted approach for subpopulations at relatively higher risk, and with targeted and/or more sophisticated involvement of primary care health professionals and healthcare centres to support such a new approach. In order to test this hypothesis, we conducted several studies using different research designs and focussing on most relevant stakeholders (screening-eligible people and GPs) and the determinants of participating. The challenges mentioned in this introduction concerning CSP participation, and as illustrated by the case of the Janssen family will be addressed in this thesis. Presented studies are part of the *Screening the CITY* project, whereby CITY is also an acronym for: ‘Cancer screening In The Hague. The influence of social and cultural determinants and health literacy on decision making’.

Chapter 2 provides a systematic overview of the literature regarding determinants of attendance and non-attendance at the CSPs in the Netherlands. This study served as an ideal starting point for this thesis by identifying current knowledge, and knowledge gaps. In **Chapter 3** we compared the CSPs aiming at breast and colorectal cancer in the city of The Hague, in order to understand the background of differing attendance rates and incidence data over a longer period of time. Hereto we gained a data-driven understanding of where possible future optimisation strategies would be needed most. **Chapter 4** presents in-depth perspectives and beliefs of screening-eligible people in The Hague, concerning cancer screening attendance. Through these perspectives and beliefs, we learned what is (most) important to screening-eligible people when it comes to participating in CSPs. In **Chapter 5** we described how important and effective a targeted proactive primary care approach can be for a specific subpopulation. We were able to conduct a cross-sectional intervention study among marginalized women in the city of Rotterdam. **Chapter 6** describes the perceptions and beliefs of GPs concerning their role and involvement in the CSPs of the Netherlands. Finally, **Chapter 7** summarizes the findings of this thesis and discusses methodologic considerations, implications, and recommendations for future research.

List of abbreviations

CRC	Colorectal Cancer
CSP	Cancer Screening Programme
EU	European Union
GP	General Practitioner
NHG	Dutch College of General Practitioners
RIVM	National Institute for Public Health and the Environment
SP	Screening Programme
WBO	Population Screening Act
WHO	World Health Organization

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