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

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CHAPTER 8

Summary

Currently, the Netherlands has three population-based cancer screening programmes (CSPs). These are the CSPs aiming at cervical, breast, and colorectal cancer. Potential participants are invited based on their age and gender to participate in these screening programmes. The primary screening methods – respectively the Pap smear/self-sampling test, bilateral mammography, and the faecal immunochemical test (i.e., stool test) – are offered free of charge to all residents registered and living in a Dutch municipality. It is known that the success of a screening programme is highly depends on the percentage of invitees who actually participate in the screening programme. According to the World Health Organization (WHO), at least 70% of invitees need to participate, without preselection, for a screening programme to be effective at the population level.

Looking at the attendance rates in the Netherlands (the latest available data is from 2022), we can conclude that the national numbers are still reasonably high; with percentages of 54.8% for the cervical cancer screening programme (CC-SP), 72.5% for the breast cancer screening programme (BC-SP), and 70.6% for the colorectal cancer screening programme (CRC-SP). However, this does not mean that the attendance rates cannot be further enhanced or that there are no further challenges regarding the attendance rates of the current screening programmes.

For years, the CC-SP has faced low attendance when we take the threshold of 70% participation into account. Additionally, there is a clear declining trend visible in the attendance rates of all three screening programmes over a period of several years. Hereby it should be noted that it might still be too early to draw this conclusion for the CRC-SP; the introduction of this screening programme dates back to 2014, and it has only been fully operational since 2019. Furthermore, significant regional differences exist in the attendance rates of the screening programmes, with particularly low rates in the major cities of the Netherlands – Amsterdam, Rotterdam, The Hague, and Utrecht. Finally, some general practitioners have informed us that they notice potential participants who might benefit the most from participating in the screening programmes are currently the least inclined to participate in the screening examinations.

Although these challenges are not unique to the Netherlands, we have chosen to focus specifically on the Dutch context in this thesis. We have focused on a multicultural urban environment, as the accessibility and inclusivity of the screening programmes seem to be under pressure here. The overarching goal of this thesis is to contribute to the future optimalization of the current Dutch screening programmes, with particular emphasis on the role of primary care (including general practitioners).

Key findings of this thesis

Although various studies have been conducted on the different factors influencing participation in the Dutch population-based cancer screening programmes (CSPs), there was no systematic literature review systematically describing, ranking, and analysing all these factors. In **Chapter 2**, we therefore begin with a systematic review in which we describe all literature published up to February 2018 regarding the characteristics of both participation and non-participation in the screening programmes. For this purpose, we searched all known and relevant electronic databases, including PubMed, Cochrane Library, and PsycINFO. Additionally, we utilized the so-called grey literature (e.g., reports from the National Institute for Public Health and the Environment (RIVM) and the national screening organisation (Bevolkingsonderzoek Nederland)). To organize all identified characteristics, we used the Integrated Change model (I-Change model) by De Vries et al. This is a model from health psychology that incorporates elements from various widely used and valued theories of health behaviour, such as the Health Belief Model, the Protection Motivation Theory, the Theory of Planned Behaviour, and the Precaution Adoption Process Model. Through this literature study, we were able to identify knowledge gaps. This study thereby formed the basis for this thesis.

The main findings arising from this study are that the previously published studies primarily tend to describe the general characteristics of (non-)attendance and (non-)attenders, but that they rarely provided in depth information on other factors of (non-)participation. We found that classic – often non-influential factors – such as socioeconomic status (SES), country of birth, and place of residence are most frequently reported and investigated in their relationship to participation in the screening programmes. Low SES, non-Western migration background, and living in an urban environment were strongly correlated with lower participation in the screening programmes. Additionally, we found that younger women and men (of course only applicable for the colorectal cancer screening programme) are less inclined to participate. Finally, we found some indications that general practitioners may be able to influence the attendance rates of the screening programmes. The I-Change model proved to be a useful tool in mapping the current knowledge about participation in the screening programmes.

In **Chapter 3**, we describe a retrospective data study to further understand which potential participants are less likely to participate in the CSPs in the city of The Hague and what risks (in terms of tumour outcomes) this entails. Due to limitations in data availability, we had to focus on the screening programmes targeting at breast cancer (BC-SP) and colorectal cancer (CR-CSP). Although it is unfortunate that we could not examine all three CSPs collectively, this did give us a unique opportunity to compare a long-standing CSP with a relatively new one. We utilized databases from the national screening organisation (Bevolkingsonderzoek Nederland) (supplemented with specific regional data via Bevolkingsonderzoek Zuid-West) and linked them to databases from the Netherlands Comprehensive Cancer Organisation (IKNL). In this study, over the period from 2005 to 2019, we were able to elucidate (at an aggregated level) who did/did not participate in the BC-SP and CRC-SP, and who ultimately was/was not was diagnosed with of one of the screening-specific tumours. For our analyses, we compared two subgroups: potential participants who did (participation >50% after invitation) and did not (participation ≤50% after invitation) participate in the screening programmes over the period.

The main findings from this study are that non-participation in the screening programmes can be directly linked to residing in a low socioeconomic status (SES) neighbourhood. Moreover, non-participation is also associated with a less favourable tumour outcome – relatively advanced tumour outcome – at the time of diagnosis. Therefore, non-participation in the screening programmes is potentially concerning and problematic, especially for certain subpopulations. When we combined the data from both screening programmes, it became clear that the majority of women do participate and generally do so consistently over time. Also, from the combined datasets, it emerged that women who did not participate in either screening programmes over time were more likely to reside in lower SES-neighbourhoods. Based on these findings, we believe that there is a need for the development of future strategies that engage specific subgroups more effectively in the screening programmes. The city of The Hague, with all its multicultural facets, proved to be an excellent setting for conducting this type of research. This is primarily due to the significant differences that exist between the various neighbourhoods in the city, which are adequately represented by the SES-scores.

In **Chapter 4**, we present a Q-methodology study (Q-study) on the beliefs and motivations of potential participants residing in the city of The Hague regarding participation in the CSPs. The idea behind this study was to clarify what is important to potential participants when they think/decide about participating in the screening programmes. A Q-study is a ‘mixed-methods’ methodology, particularly used to gain insight into prevailing perspectives on specific subjects within certain populations. Due to the COVID-19 pandemic outbreak, we conducted our Q-study online using an existing research panel. In a Q-study, respondents are presented with a set of statements that they must rank based on their beliefs within a predetermined framework. These rankings (one ranking per participant) thus form the quantitative data. Subsequently, factor analysis is conducted to identify significant clusters of correlations. The assumption is that respondents with similar perspectives will rank the statements in similar ways. The qualitative data is formed by respondents providing explanations for their rankings. In our study, we also interviewed selected respondents after they completed their rankings. We identified three different perspectives. The first identified perspective was labelled as ‘positive about participation’. These are the people who typically always participate in the screening programmes. They have a positive attitude towards the screening programmes, and respondents indicated that participation in the screening programmes is part of their (social) norm. Interestingly, the interviewed respondents with this perspective could not always provide correct information about the screening programmes, particularly not about the medical follow-up tests. Therefore, we questioned whether their decision to participate in the screening programmes is the result of a deliberate, well-informed choice. The second perspective was labelled as ‘thoughtful about participation’. People with this perspective were found to be more hesitant about participating in the screening programmes. They more often doubted the effectiveness of the screening programmes and considered the potential consequences of screening (including false-positive and false-negative results) more important. These respondents were generally better informed about the potential consequences of the screening programmes. Unique to this perspective is the role that respondents see for their general practitioner/primary care provider(s) as advisors. The third perspective was labelled by us as ‘fear drives participation’. These people mostly participate in the screening programmes, but this is mainly due to feelings of fear and discomfort. Most respondents with this perspective knew people who had actually suffered from or died from the consequences of cancer. Respondents may have felt more vulnerable to being diagnosed with cancer themselves. People with this perspective were less open to external influence and guidance.

The main findings from this Q-study are that beliefs and motivations about the screening programmes not only differ between participants and non-participants, but also can differ between subgroups of people with different underlying perspectives. We believe that it is meaningful to adjust communication about the screening programmes to the perspectives of potential participants. For people belonging to perspective 1 (positive about participation), more attention should be paid to providing information about the screening programmes and the medical follow-up tests. For perspective 2 (thoughtful about participation), more attention should be paid to the potential drawbacks of screening. For perspective 3 (fear drives participation), more attention should be paid to the risks (and numbers) associated with participation in the screening programmes. For two of the perspectives in this study, communication channels outside of primary care seem suitable. However, for respondents belonging to the second perspective, who are doubtful about participating in the screening programmes, it appears that they value information provided by a general practitioner or other trusted primary care provider.

In **Chapter 5**, we demonstrate the importance and effectiveness of a specific invitation strategy for vulnerable subpopulations. Therefore, we consider this study a ‘proof of concept study’. In the city of Rotterdam, we conducted a cross-sectional intervention study, inviting marginalized women to participate in a screening study for cervical cancer. For this study, women were considered marginalized if they had not received, or could not receive, invitation letter(s) for the cervical cancer screening program (CC-SP) due to their living conditions. Our study focused on sex workers in unstable conditions, homeless women, and women without official documentation. In total, we were able to collect samples from 74 women for this study. The collected samples were analysed for both the presence of high-risk human papillomavirus (hrHPV) and cytological abnormalities. In doing so, we intentionally deviated from the standard practice within the current CC-SP. We compared the results of the samples we collected with regional prevalence data from women who had participated in the CC-SP. We obtained this data through the national screening organisation, region South-West (Bevolkingsonderzoek Zuid-West).

The main findings from this study are that marginalized women seem to have a four times higher risk of hrHPV infection with cytological abnormalities compared to women screened through the CC-SP. Additionally, through this study, we demonstrated that a direct proactive approach is by far the most effective way to reach marginalized women. In our study, 92% of all women were included for participation in the study through this proactive approach. Based on this study, we believe that much more attention should be paid to vulnerable women without stable housing in relation to the development of (precursors to) cervical cancer.

Since our earlier studies suggested that primary care providers might play an important role in optimizing participation rates of the CSPs, in **Chapter 6**, we focused on general practitioners (GPs) and surveyed them about their current role regarding the CSPs and whether they believe it should be different. For this purpose, we conducted a stepped ‘mixed-methods’ study by first developing a questionnaire and distributing it among GPs. Subsequently, we interviewed a selected number of GPs using semi-structured in-depth interviews to interpret the data resulting from these questionnaires.

The main findings from this study are that GPs generally hold a positive view of CSPs and their role therein. Furthermore, GPs indicated their willingness to further support and reinforce the CSPs. However, they clearly stated their reluctance to take on (additional) logistical and organizational tasks. A proactive neighbourhood-based approach emerged as one of the possible options to optimize the current screening programmes. In this regard, GPs emphasized the need to pay more attention to involving people residing in low socioeconomic status (SES) neighbourhoods. The most innovative idea to achieve this was the concept of an ‘add-on methodology’, whereby GPs/general practices themselves selectively invite patients, as a supplement to the general invitation for participation in the CSPs. The most positive effects are likely to be expected when GPs select patients whom they assess to be at (higher) risk of developing one of the screening-specific tumours.

Conclusion

The studies described in this thesis provide additional evidence that the current Dutch population-based screening programmes (CSPs) can be further optimized, particularly concerning the participation of potential participants from highly urbanized and low socioeconomic status (SES) neighbourhoods. Our findings suggest that non-participation in the CSPs in these low SES-neighbourhoods is associated with more unfavourable, relatively advanced, tumour outcomes. Given that the decision to participate in a CSP is not solely based on rational decision-making processes, primary care providers could play an important role here. This would primarily involve informing and advising potential participants who are hesitant about participating in CSPs. In this thesis, we describe that both potential participants and general practitioners support the idea that primary care should be more involved in the invitation process of the CSPs. Based on our findings, we therefore recommend implementing a proactive, risk-based invitation strategy from primary care regarding the invitation process of the current CSPs.