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Original research

Socio-demographic and cultural factors related to non-participation in the Dutch colorectal cancer screening programme

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Abstract ***Background:*** High participation rates are essential for a screening programme to be beneficial. To reach non-participants in a targeted manner, insight in characteristics of non-participants is needed. We investigated demographic differences between participants and non-participants in the Dutch faecal immunochemical test-based colorectal cancer (CRC) screening programme.

Methods: In this population-based cohort study, we included all invitees for CRC screening in 2018 and 2019. Participation status, birth year, and sex were extracted from the Dutch national screening information system and linked to demographic characteristics from Statistics Netherlands, including migration background, level of education, socioeconomic

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category, household composition, and household income. A multivariable logistic regression was used to assess the association between demographic factors and participation.

Results: A total of 4,383,861 individuals were invited for CRC screening in 2018 and 2019, of which 3,170,349 (72.3%) participated. Individuals were less likely to participate when they were single and/or living with others (single with other residents versus couple: odds ratio [OR] 0.34, 95% confidence interval [CI]: 0.31–0.38), had a migration background (e.g. Moroccan migrant versus Dutch background: OR 0.43, 95% CI: 0.42–0.44), or had a low income (lowest versus highest quintile: OR 0.45, 95% CI: 0.44–0.45). Although to a lesser extent, non-participation was also significantly associated with being male, being younger, receiving social welfare benefits and having a low level of education.

Conclusion: We found that individuals who were single and/or living with others, immigrants from Morocco or individuals with low income were the least likely to participate in the Dutch CRC screening programme. Targeted interventions are needed to minimise inequities in CRC screening.

1. Introduction

Colorectal cancer (CRC) screening has been proven effective in the prevention and early detection of CRC [1]. As such, screening may reduce the burden of disease and prevent CRC-related death [2]. For a screening programme to be beneficial, high and consistent participation rates are essential [3,4]. Population-based CRC screening has been introduced in the Netherlands in 2014, inviting individuals aged 55 to 75 biennially for faecal immunochemical test (FIT)-based screening. Although the participation rate is one of the highest globally [5], participation dropped slightly from 73.3% in 2016 to 70.6% in 2021 [5–7].

There is a considerable amount of literature on factors related to non-participation in CRC screening. As such, it has been shown that individual's demographic characteristics are more strongly associated with participation than organisational factors of a screening programme, such as screen-test modality and test frequency [8]. For example, male sex and having a non-Western migration background are proven to be associated with non-participation [9–11]. Up to now, studies that investigated factors related to non-participation in the Netherlands were only based on age, sex, and postal code of invitees: van der Meulen et al. found that a lower area-level socioeconomic status (SES) was associated with lower participation [12], and de Klerk et al. found that the willingness to participate was lower in areas with a high urban density [13]. However, these factors are still relatively broad, and insight into the effect of other demographic factors on participation is needed to develop a tailored approach to reach non-participants in the Dutch CRC screening programme.

We therefore aimed to investigate individual-level demographic differences between participants and non-participants in the Dutch CRC screening programme.

2. Methods

2.1. The Dutch setting

Population-based CRC screening has been introduced gradually in the Netherlands since 2014, offering biennial FIT-based screening. After a phased rollout period between 2014 and 2017, the entire target population of 55- to 75-year-olds was invited from 2018 onwards. All screen-eligible individuals who are registered in the Netherlands are invited through the use of the Dutch Personal Records Database (BRP). Invitation packages containing an invitation letter, a FIT kit, and a prepaid return envelope are mailed to the invitees. First-time invitees receive a notification letter prior to their first invitation. Non-responders receive a reminder after 6 weeks. All primary correspondence is in Dutch, but the Dutch National Institute for Public Health and the Environment provides all information materials on their website in Dutch, English, Turkish, Arabic, Ukrainian, and Russian, and the Dutch screening organisation provides additional information about the screening programme on their website in Dutch, English, Turkish, and Arabic. Participation in the screening programme is free of charge. In 2020, the programme was suspended from March till May due to the COVID19-pandemic [14]. The backlog was caught up in 2021. More details on the Dutch CRC screening programme can be found elsewhere [15,16].

2.2. Study population

All invitees to the Dutch CRC screening programme in 2018 and 2019 were included in this study. We intentionally selected invitees in 2018 and 2019 to ensure that the entire target population was invited once during our study period, since this was the first invitation round

after the phased rollout period but before the suspension of the screening programme due to the pandemic. Of these invitees, participation status, birth year, and sex were selected from the Dutch screening information system (ScreenIT). The invitees were linked to demographic characteristics from Statistics Netherlands (Centraal Bureau voor de Statistiek, CBS) based on their unique Dutch personal identification number. Data on these characteristics were retrieved on 1st January 2019, and included municipality, migration background, level of education, household characteristics, SES, and income. CBS managed the linking process and made the anonymized data available to the researchers.

2.3. Definitions

A *participant* was defined as an invitee who returned the FIT. The *participation rate* was defined as the percentage of invitees that participated in the CRC screening programme. *Age* was determined by subtracting an individual's birth year from the year of invitation to screening.

2.3.1. Migration background

Migration background was based on two different variables: country of origin and generation of the migrant. A first-generation migrant was defined as a person who was born abroad and has at least one parent who was also born abroad, whereas a second-generation migrant was a person who was born in the Netherlands with at least one parent born abroad, following the CBS classification. We subdivided migration background into different categories using the most common countries of origin in our data: The Netherlands, Germany first generation, Germany second generation, Dutch East Indies first generation, Dutch East Indies second generation, Surinam first generation, Surinam second generation, Turkey, Morocco, Other first generation, and Other second generation. The distinction by generation was not made for migrants from Turkey and Morocco, since these migrants were almost exclusively first-generation migrants in our sample (99.8% of the Turkish migrants and 99.9% of the Moroccan migrants).

2.3.2. Level of education

Level of education was divided in the categories low (e.g. primary education and preparatory secondary vocational education), medium (vocational education and training), and high (university) according to the CBS definition [17].

2.3.3. Socioeconomic category

Socioeconomic category was classified as retired, employed (either self-employed or employee), receiving social welfare, and other.

2.3.4. Household income and SES

Household SES score was based on financial welfare, level of education, and employment history [18]. For the sake of interpretability, both household income and SES score were divided into quintiles, with the highest values in the first quintile and the lowest values in the fifth quintile.

2.3.5. Household characteristics

The number of people living in a household was divided into four categories: 1, 2, 3, and 4 or more persons. Household type was divided into eight categories: couple, single-person, couple with child(ren), single parent with child(ren), couple with other residents, single with other residents, institutional household, and other multiperson household.

2.4. Analyses

Differences in demographic characteristics between participants and non-participants were tested using a Chi-squared test. The effect of each factor on participation was estimated in a multivariable logistic regression with participation as dependent variable (0 for non-participation and 1 for participation). The variance inflation factor (VIF) was used to identify strongly correlated explanatory variables. Variables with VIF > 5 were not included simultaneously within one model. Model selection was based on the Akaike Information Criterium (AIC), and the model with the lowest AIC score was chosen. Odds ratios were calculated for the final model. A significance level of 5% was used throughout.

3. Results

3.1. Demographic characteristics

A total of 4,383,861 individuals were invited for CRC screening in 2018 and 2019, of which 3,170,349 (72.3%) participated. The linkage rate was 100%, implying that all ScreenIT records could be matched with a unique CBS identifier. Males comprised 49.3% of the sample and the mean age of invitees was 63.9 (standard deviation 6.3) years. All demographic characteristics were statistically different between participants and non-participants. Both Fig. 1 and the participation rates in Table 1 show that the participation rate was lower among males, younger invitees, individuals with a migration background, single persons and singles or couples living in a household with other residents, individuals with a lower level of education, recipients of social welfare benefits, individuals with a lower income, and individuals with a lower SES score. For example, participation was 44.6% in individuals with a Moroccan migration background versus 74.7% in individuals with a Dutch background; 55.7% in single persons living with other residents versus 78.9% in couples in a two-person household; and 55.7% in individuals

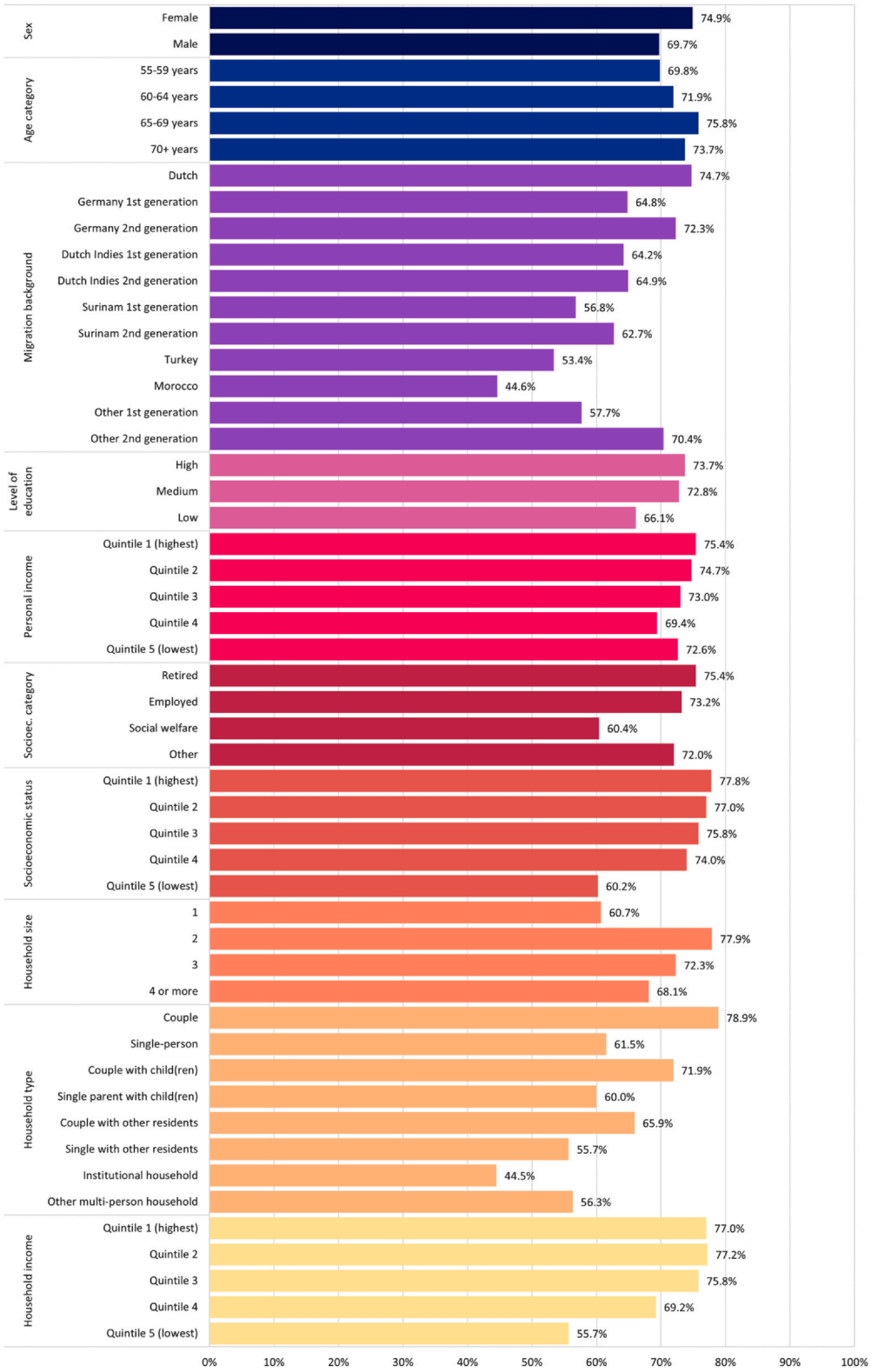

Fig. 1. Participation rates per demographic group.

in the lowest income quintile versus 77.2% in individuals in the second quintile. Of all invitees with a migration background, relatively more German migrants and less Turkish and Moroccan migrants participated in the screening programme.

3.2. Regression outcomes

The final logistic regression model included sex, age category, migration background, level of education, socioeconomic category, household type, and household

Table 1
Participation rate and odds ratio per explanatory variable.

Variable	N	Participation rate	Odds ratio (95% CI)
Sex			
Female	2,223,274	74.9%	*Ref*
Male	2,160,587	69.7%	0.68 (0.68–0.69)*
Age category			
55–59 years	965,695	69.8%	*Ref*
60–64 years	841,358	71.9%	1.10 (1.09–1.11)*
65–69 years	1,091,904	75.8%	1.24 (1.23–1.26)*
70+ years	968,943	73.7%	1.17 (1.15–1.19)*
Migration background			
Dutch	3,654,730	74.7%	*Ref*
Germany first generation	14,085	64.8%	0.66 (0.62–0.70)*
Germany second generation	85,545	72.3%	0.92 (0.89–0.94)*
Dutch East Indies first generation	18,205	64.2%	0.56 (0.53–0.59)*
Dutch East Indies second generation	93,120	64.9%	0.67 (0.65–0.68)*
Surinam first generation	76,147	56.8%	0.64 (0.62–0.65)*
Surinam second generation	3,974	62.7%	0.66 (0.59–0.73)*
Turkey	52,258	53.4%	0.62 (0.60–0.64)*
Morocco	46,924	44.6%	0.43 (0.42–0.44)*
Other first generation	285,454	57.7%	0.68 (0.67–0.68)*
Other second generation	53,412	70.4%	0.86 (0.83–0.89)*
Level of education			
High	543,109	73.7%	*Ref*
Medium	688,614	72.8%	1.05 (1.04–1.06)*
Low	626,987	66.1%	0.90 (0.89–0.91)*
Socioeconomic category			
Retired	1,852,285	75.4%	*Ref*
Employed	1,807,886	73.2%	0.89 (0.88–0.90)*
Social welfare	485,889	60.4%	0.81 (0.80–0.83)*
Other	202,185	72.0%	0.77 (0.76–0.79)*
Household type			
Couple	2,355,207	78.9%	*Ref*
Single-person	922,331	61.5%	0.61 (0.61–0.62)*
Couple with child(ren)	775,227	71.9%	0.68 (0.67–0.69)*
Single parent with child(ren)	141,561	60.0%	0.46 (0.45–0.46)*
Couple with other residents	81,840	65.9%	0.49 (0.48–0.51)*
Single with other residents	3,991	55.7%	0.34 (0.31–0.38)*
Other multi-person household	34,758	56.3%	0.36 (0.35–0.38)*
Household income			
Quintile 1 (highest income)	1,031,980	77.0%	*Ref*
Quintile 2	982,129	77.2%	0.87 (0.86–0.88)*
Quintile 3	1,033,933	75.8%	0.77 (0.76–0.78)*
Quintile 4	755,868	69.2%	0.60 (0.59–0.60)*
Quintile 5 (lowest income)	502,301	55.7%	0.45 (0.44–0.45)*

Abbreviations: CI = confidence interval; Ref = reference category.
* Significant at a significance level of 5%.

income as explanatory variables (Table 1). Household size and SES score were not included in the model due to multicollinearity with household type and household income, respectively. The model confirmed that participation was lower for invitees who were single and/or living with other residents compared to a couple in a two-person household (odds ratio [OR] single with other residents versus couple: 0.34 [95% confidence interval [CI]: 0.31–0.38]). Moreover, compared to invitees with a Dutch background, participation was lower in first-generation migrants from the Dutch East Indies (OR: 0.56 [95% CI: 0.53–0.59]), Surinam (OR: 0.64 [95% CI: 0.62–0.65]), Turkey (OR: 0.62 [95% CI: 0.60–0.64]), and Morocco (OR: 0.43 [95% CI: 0.42–0.44]). Second-generation migrants showed higher participation than first-generation migrants, but still lower than invitees with a Dutch background. Furthermore, participation decreased with income (OR fifth versus first quintile: 0.45 [95% CI: 0.44–0.45]) and participation was lower in males than in females (OR male versus female: 0.68 [95% CI: 0.68–0.69]). Although to a lesser extent, participation was significantly higher for older invitees (OR 60–64, 65–69 and 70+ versus 55–59 years: 1.10 [95% CI: 1.09–1.11], 1.24 [95% CI: 1.23–1.26] and 1.17 [95% CI: 1.15–1.19] respectively), and lower for employed invitees and recipients of social welfare benefits compared to retired invitees (OR employed and social welfare versus retired: 0.89 [95% CI: 0.88–0.90] and 0.81 [95% CI:

0.80–0.83], respectively), as well as for invitees with a low level of education (OR low versus high level of education: 0.90 [95% CI: 0.89–0.91]). The relation between participation and both age and education level was U-shaped; after an increase for the lowest levels, it decreased for the highest age group and highest education level.

4. Discussion

This study demonstrated that being single and/or living with other residents, having a migration background, low income, and male sex were negatively associated with participation in a FIT-based CRC screening programme. This unveils, at least in part, the relationship between inequity and CRC screening, and our results may suggest that the screening programme increases inequity rather than reducing it.

Of all the factors accounted for in our analysis, singles living with other residents were the least likely to participate. The finding that singles participate less is consistent with the idea that married people have a healthier lifestyle. Moreover, there is more social control within couples [19]. Secondly, the odds of participation decreased with up to 57% for individuals with a migration background compared to individuals with a Dutch background. In particular migrants from Morocco, Turkey, and first-generation migrants from Surinam and the Dutch East Indies participated less. Possible explanations for this lower participation include a language barrier, (cultural) differences in health beliefs, and the level of acculturation [20,21]. The effect of acculturation is confirmed by the fact that participation was higher for second-generation migrants than for first-generation migrants. Thirdly, the odds of participation were 55% lower in the lowest income group compared to the highest income group. A possible explanation is that low-income groups consider potential costs of colonoscopy in case of a positive test result when deciding whether or not to participate [22]. In the Netherlands, the FIT test is free, but colonoscopy is paid for through health insurance and this is susceptible to a deductible between 385 and 885 Euros. Also, low-income groups are known to have less knowledge of (the risk of) CRC and the effect of screening [23]. Lastly, the odds of participation was 32% lower in men than in women. Potential reasons for this include a lack of confidence in the screening test and lower self-efficacy among men [24]. Another possible explanation is that women have previously been exposed to screening due to invitation to breast and cervical cancer screening at a younger age, which could enhance participation [8].

Our results are in line with existing literature [9–11,25–30]. Also the U-shaped associations between participation and age, and participation and level of education have been observed elsewhere [11,27]. Looking at the migration background of invitees, previous research demonstrated that non-Western immigrants are less likely to participate in CRC screening than Western immigrants [10,11], and even within these categories participation rates differ [27]. Our study adds to the existing body of literature that first-generation migrants show lower participation than second-generation migrants. Regarding household type, previous studies confirmed that single persons are less likely to participate compared to those who have a registered partner [10,11,19]. We differentiated even more within these categories and demonstrated that cohabitation with children and/or other residents decreased participation further, for both single persons and those with a partner.

One of the main strengths of this study is the comprehensiveness and reliability of our data. The data contained information of over 4 million invitees of a nationwide population-based screening programme and covered the entire target population. Moreover, since our study was registry-based, potential biases due to self-report were nullified. Lastly, individual-level data were available for all variables. Apart from the quantity and quality of the data, the multivariate design of our model allowed us to take multiple demographic factors into account simultaneously. This is an advantage compared to previous studies in the Netherlands, which only estimated the relation between SES and participation [12], and urban density and participation [13].

Nonetheless, our study has several limitations. First, there was no information on comorbidities available. This may have led to a slight underestimation of the participation rate, since non-participants might have had a valid reason to not participate in screening. In addition, since comorbidities may be related to both participation and receiving welfare benefits, the absence of information on comorbidities may have led to confounding bias in the estimated association between socioeconomic category and participation. Secondly, there may be heterogeneity within the different migration background groups due to unobserved factors such as the time since migration and the level of acculturation. However, by differentiating between different countries of origin and between first- and second-generation migrants, we aimed to minimise this heterogeneity.

Participation rates should be high enough for the screening programme to be effective. Moreover, some of the underserved groups are known to have a higher a priori risk of CRC [12,13], so the yield of screening could potentially be higher in these groups than in the general population. It is therefore important that these groups, as well as the entire target population, are adequately informed about the benefits and harms of CRC screening. This is confirmed by a previous study, which showed that only 12% of the non-participants in CRC screening in the Netherlands made an informed choice [31].

Now that we have identified the underserved groups, targeted interventions are needed to ensure that these

groups are reached well. Several initiatives have been proven effective already. For example, implementing theory-based modifications to the advance notification letter led to an increase in participation among males [32]. Additionally, interviews among ethnic minority women in Denmark showed that information provided in their native language may improve knowledge of screening [33]. Nonetheless, the effect of interventions should be monitored carefully, since the impact may be ambiguous. For instance, sending out reminders after non-participation decreased differences in participation between age groups, but slightly increased differences in participation between income quartiles [34]. Furthermore, tailored information on the benefits and harms of CRC screening may have to be disseminated in an alternative fashion, as the majority of non-participants reported that they did not read the standard information booklet [35]. Lastly, certain demographic subgroups may be more challenging to target in particular, such as single persons.

Apart from targeted interventions to reach non-participants, future research should investigate the background CRC risk and screening yield of the underserved groups, in order to estimate the potential health gain achieved when participation rates would increase in these groups. This will help prioritise who should be targeted first. For males and individuals with a low SES, it has already been shown that they are at higher risk of CRC [12,36]. Future research should investigate whether that is the case for the other groups as well, such as individuals with a migration background. In addition, future research should identify reasons for non-participation within different demographic subgroups, such as culture-specific barriers for specific immigrant groups. Interventions can then be designed accordingly, as has been done for cervical cancer screening in the Netherlands recently [37].

In conclusion, we have identified the non-participants in the Dutch CRC screening and found that singles living with others, Moroccan migrants, and individuals with a low income participated the least. The next step is to take action to reach the underserved groups better. Nationwide multimedia campaigns, local initiatives focussing on specific underscreened communities, and a combination of both should be considered [38]. Examples include culturally sensitive educational information materials and multiwave integrated national media campaigns [37,39].

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CRediT authorship contribution statement

HJvdSV, ETZ, and ILV conceptualised the study and contributed to the study design. HJvdSV performed the analyses and accessed and verified the data. HJvdSV wrote the draft version of the manuscript, with supervision from ETZ. All authors contributed to reviewing drafts of the manuscript and approved the final manuscript draft.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: ED: Received endoscopic equipment on loan of Olympus and FujiFilm and research grant from FujiFilm; received honorarium for consultancy from FujiFilm, Tillots, Olympus, GI Supply, Cancer Prevention Pharmaceuticals, PAION, and Ambu; and a speakers' fee from Olympus, Roche, GI Supply, PAION, and IPSEN. ILV: Associate editor at Gastroenterology; expert at the Health Council; panel member of the European Commission Initiative on Colorectal Cancer; visiting scientist at IARC. MS: Received research support from Sentinel, Sysmex, Boston Scientific, Norgine, and Medtronic. All other authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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