



## Investigating the decrease in participation in the Dutch cervical cancer screening programme: The role of personal and organisational characteristics

Clare A. Aitken<sup>a,1,\*</sup>, Sylvia Kaljouw<sup>a,1</sup>, Albert G. Siebers<sup>b,c</sup>, Matilde Bron<sup>d</sup>, Anne Morssink<sup>e</sup>, Folkert J. van Kemenade<sup>f</sup>, Inge M.C.M. de Kok<sup>a</sup>

<sup>a</sup> Department of Public Health, Erasmus MC University Medical Center, Dr. Molewaterplein 40, 3015 CN Rotterdam, the Netherlands

<sup>b</sup> PALGA, the Nationwide Network and Registry of Histo- and Cytopathology in the Netherlands, Randhoeve 225A, 3995 GA Houten, the Netherlands

<sup>c</sup> Department of Pathology, Radboud University Medical Center, P.O. Box 9101, 6500 HB Nijmegen, the Netherlands

<sup>d</sup> Bevolkingsonderzoek Noord, Queridolaan 5, 9721 SZ Groningen, the Netherlands

<sup>e</sup> Bevolkingsonderzoek Oost, Zutphenseweg 51, 7418 AH Deventer, the Netherlands

<sup>f</sup> Department of Pathology, Erasmus MC University Medical Center, Dr. Molewaterplein 40, 3015 CN Rotterdam, the Netherlands

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### ABSTRACT

Declining attendance in the Dutch cervical cancer screening programme was recently observed, coinciding with preparations for implementing primary hrHPV-based screening, which was implemented in January 2017. We aimed to investigate which factors were related to decreased attendance. We conducted a population-based cohort study including all women aged 30 to 60 years who were eligible for screening between 2014 and 2018. Attendance was defined as participation in the screening programme within 15 months of the start of the invitation-eligible year. We used data from the Dutch pathology archive (PALGA) linked with data from Statistics Netherlands to investigate population characteristics (position in the household, household income, socio-economic status, number of people in the household, migration background, age) and data from the five Dutch screening organisations (SO) to investigate the effect of ceasing self-inviting GP's ('inviting organisation'). SO's were termed SO 1 to 5. Higher attendance rates were observed in women who were employed (60.8%), married (62.9%), Dutch (61.2%), in the highest income bracket (63.4%), living in households with four persons (65.3%) and women who were invited by their GP (69.8%). Differences in personal characteristics did not explain the decline in attendance rates. By adjusting for whether the GP or the SO sent the invitation, the differences in attendance rates between 2014 and 2015 and 2016 and between 2014 and 2015 and 2017–2018 were explained in some screening organisations. Removing the possibility for GPs to send invitations explains some of the decline in participation, although this did not account for the total change in attendance.

### 1. Introduction

Organised cancer screening programmes are only able to provide maximum benefit to the population if attendance is high. Women who do not participate in cervical cancer screening make up the majority of cervical cancer diagnoses (Bos et al., 2006). Therefore, monitoring the attendance rate is an important part of quality assurance in organised screening programmes.

In the Netherlands, participation in the cervical cancer screening programme had been relatively stable. Over the period 2012 to 2015, attendance rates ranged between 64.4% and 66.2% (Erasmus MC & PALGA, 2017). In January 2017, a new high-risk human papillomavirus (hrHPV) based screening programme was introduced nationwide. The implementation took place over the first quarter of 2017, however, some changes were already made in 2016 (e.g. accelerated invitations, reminders were stopped earlier, women could only participate until 1

*Abbreviations:* RR, relative risk; PALGA, The nationwide network and registry of histo- and cytopathology in the Netherlands; SO, screening organisation; GP, general practitioner; CBS, Statistics Netherlands.

\* Corresponding author at: Office Be332a, Erasmus MC University Medical Center, Dr. Molewaterplein 40, 3015 CN Rotterdam, The Netherlands.

E-mail address: [c.aitken@erasmusmc.nl](mailto:c.aitken@erasmusmc.nl) (C.A. Aitken).

<sup>1</sup> These authors contributed equally to this study.

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December 2016, GP invitations were stopped). Given the changes in 2016, a lower participation rate was not surprising (60.3%) (Erasmus MC & PALGA, 2017), however following the first year of the new programme, attendance declined further (2017: 57.4%) (Erasmus MC & PALGA, 2018). Screening organisations anticipated some catch up attendance because of the transition. However, in 2018, the attendance rate remained below 60% (Netherlands Cancer Registry, 2019). Lower participation in the new programme was unexpected, as hrHPV self-sampling is now offered as an alternative screening method for women who did not feel comfortable with being screened by their general practitioner (GP). Self-sampling has been shown to be a promising strategy to encourage participation amongst non-responders to regular screening programme invitations (Gok et al., 2010; Broberg et al., 2014).

When the new screening programme was introduced, day-to-day management was streamlined. All five screening organisations in the Netherlands (SO; responsible for the implementation of the programme across five geographical regions) implemented standardised invitation and reminder policies, after which all invitations were sent by the SO's following the birthdate of each eligible woman. Previously, some general practices sent invitations to their patients on behalf of the SO's and the time of the year when women were invited varied.

Changes to both the primary test and policies seem to have affected attendance, however it is unclear what is driving the change. We aimed to investigate this by analysing attendance rates and attenders in the Dutch cervical screening programme leading up to, during, and after the implementation of the new hrHPV-based screening programme. Specifically, we aimed to investigate what factors influence attendance, and what factors have influenced the decrease in attendance between 2014 and 2018.

## 2. Materials and methods

### 2.1. Setting

Organised cervical cancer screening has been offered in the Netherlands for more than thirty years. Since 1996, women aged 30 to 60 years have been invited to participate every five years. Before 2017, women were screened using cervical cytology. Starting in 2017, hrHPV-based primary screening was implemented, including the option of self-sampling.

### 2.2. Participants

All women aged 30 to 60 years who are living in the Netherlands are invited for screening every five years. Women who were eligible to receive an invitation for screening in years 2014 to 2018 based on their year of birth were included in our study (Table A1).

### 2.3. Data sources

We used two datasets that each combined two data sources; one dataset containing information about population characteristics and one dataset containing information about organisational factors. Detailed information about the contents of each dataset is outlined below. For legal and practical reasons, linkage between population characteristics data and organisational factors data was not possible. Therefore, we conducted separate, parallel analyses with the two datasets.

#### 2.3.1. Population characteristics

To investigate population characteristics, we linked data from the nationwide network of cyto- and histopathology (PALGA) with socioeconomic information from Statistics Netherlands (Centraal Bureau voor de Statistiek, acronym CBS). This dataset is further referred to as PALGA/CBS (Fig. 1). PALGA has complete coverage of all pathology labs in the Netherlands (Casparie et al., 2007). We selected primary screening tests of women who participated in 2014–2018. Screening tests that were recorded within 15 months of the start of year of invitation eligibility were included (e.g. for women eligible for invitation in 2014, smears recorded between 1 January 2014 and 31 March 2015 were included). We requested that CBS select data for women in the target population for screening (Table A1). Deterministic linkage was used. 99.3% of PALGA records could be matched with a CBS identifier. The linkage rate between the two datasets was 57.4%, because non-attenders had no information in PALGA.

NB. Each cell represents information from one unique woman invited for screening. Orange box contains the party that was responsible for data linkage. Yellow rows represent cases that are defined as 'non-attenders'.

Information about personal characteristics (migration background, income, socioeconomic status and household composition) was provided for each year (2014 to 2018) that a woman had data recorded in CBS; therefore, each woman in the dataset had a maximum of five values for each variable. We assigned each record to a screening invitation year

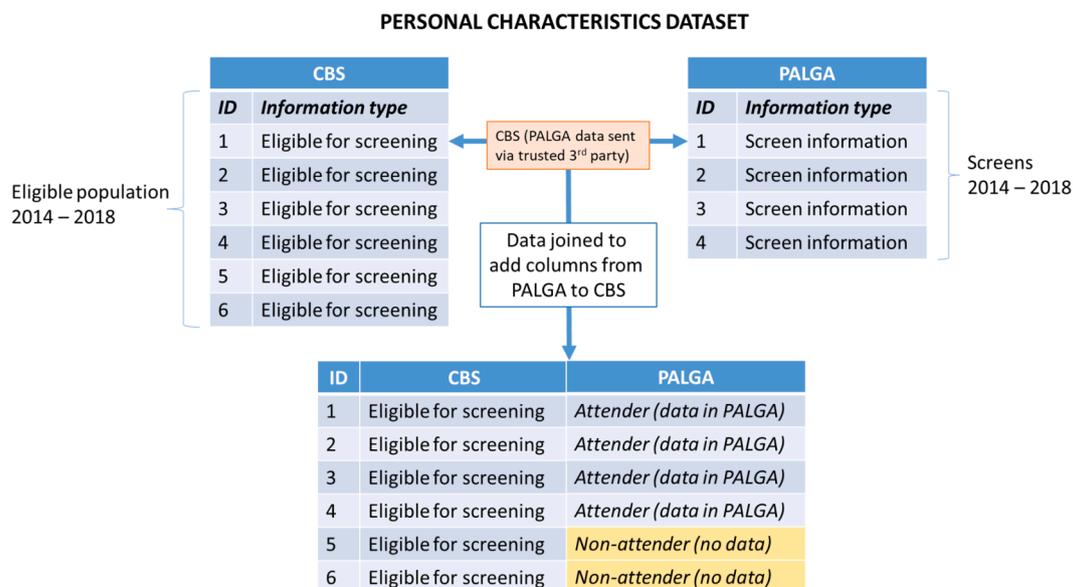


Fig. 1. Process to create PALGA/CBS dataset.

(2014–2018) based on their age on 1 January (i.e. a woman was allocated to 2014 if her age was 29, 34, 39, 44, 49, 54 or 59 years on 1 January 2014). Based on the invitation year, we selected values for each CBS variable for each woman.

### 2.3.2. Organisational factors

In order to classify organisational factors, we obtained data from the five SO's about all invitations sent during the period 2014–2018. This dataset was the result of merging two registries; one used in the new hrHPV-based programme ('ScreenIT') and one used in the old cytology-based programme ('CIS'). This dataset is further referred to as **ScreenIT/CIS** (Fig. 2). This dataset included information about date of invitation, participation and inviting organisation (SO or GP).

NB. Each cell represents information from one unique woman invited for screening. Orange box contains the party that was responsible for data linkage. Yellow rows represent cases that are defined as 'non-attenders'.

## 2.4. Data definitions

We defined attenders as women who had a screening test within 15 months of the beginning of the year of invitation (e.g. for women eligible for invitation in 2018, attenders had screens recorded between 1 January 2018 and 31 March 2019). Non-attenders were women without a screening test recorded. In practice, this was done slightly differently in each dataset. In PALGA/CBS data, non-attenders were defined as women who are in the target population (i.e. in CBS) but did not have a matched link between PALGA and CBS (i.e. not in PALGA; Fig. 1). In ScreenIT/CIS, non-attenders were all women who were invited but did not have a screen recorded within 15 months of the start of the invitation year. There were a higher number of attenders in ScreenIT, but fewer non-attenders compared to PALGA/CBS (Fig. A1).

In both datasets, we combined invitation year into three categories; the old cytology-based programme (2014–2015), the transition year (2016) and the new hrHPV-based programme (2017–2018).

We named the five SO's SO 1 to 5 in order to pseudonymise them. The SO that a woman is allocated to is based on the council area in which the woman lives. SO is automatically recorded in PALGA and ScreenIT/CIS. For non-attenders in PALGA/CBS, there was no SO region information. We had information about city council area for each woman

from CBS and a concordance between SO regions and city council areas from PALGA. Using this information, we were able to allocate non-attenders to a SO.

### 2.4.1. Population characteristics

Socio-economic status was determined by CBS based on income source. If a person has multiple sources of income in a particular year, the income source that contributes the largest amount is used to classify this variable into one of 14 categories. We grouped this variable into broader categories: employed; not employed, social welfare; not employed, in education; no income.

Position in the household was determined by CBS by comparing each household member to the main breadwinner and was classified as: breadwinner without partner; breadwinner with partner; married partner; unmarried partner; adult child; other household member.

We classified the number of people living in a household into six categories: one; two; three; four; five; six or more.

Standardised household income percentile was calculated by CBS for private households, excluding student houses. We grouped this variable into four categories: 1–24%; 25–49%; 50–74%; 75–100%.

For migration background, we combined CBS variables 'migration generation' and 'country of origin'. Migration generation was determined by country of birth of women themselves and their parents; a person was classified as Dutch if both parents were born in the Netherlands, a first generation migrant was a person who was born abroad and has at least one parent who was also born abroad and a second generation migrant was a person who was born in the Netherlands with a least one parent born abroad. Country of origin was determined by the country of birth of either the woman's parents or themselves. Country of origin was classified by CBS into 'Western' (Europe excluding Turkey, North America, Oceania, Indonesia and Japan) and 'non-Western' (Africa, Latin America and Asia [excluding Indonesia and Japan] and Turkey) (Statistics Netherlands (CBS), 2020). Based on these two variables, we categorised women into the following groups: Dutch; non-Western, first generation; non-Western, second generation; Western, first generation; Western, second generation.

### 2.4.2. Organisational factors

Inviting organisation was automatically recorded in ScreenIT/CIS. This could be either the SO or the woman's registered general practice.

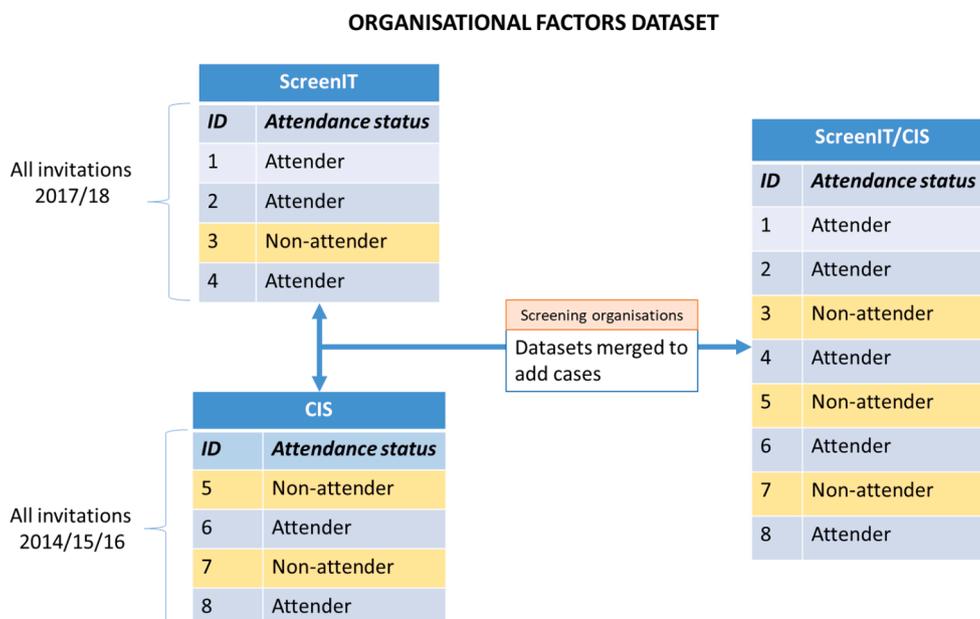


Fig. 2. Process to create ScreenIT/CIS dataset.

GPs could only send screening invitations in the old cytology-based programme. This practice stopped in 2016. Table A2 contains information on the proportion of invitations sent by self-inviting GP practices.

## 2.5. Statistical analysis

Data management and analysis was conducted using IBM SPSS Statistics for Windows v25 (Armonk, NY, IBM Corporation) and RStudio (using R v.3.6.2; Boston, MA). Because our endpoint, attendance, has high prevalence in our population (~60%), odds ratios would have been overinflated (Zhang and Yu, 1998). Due to this, we performed multivariate Poisson regression analysis. To control for the fact that invitation and reminder policies were directly related to SO between 2014 and 2016 (see Table A2), we calculated one model per SO.

### 2.5.1. Population characteristics

We used R package ‘mice’ to impute missing values in ‘standardised income percentile’ using five iterations (van Buuren and Groothuis-Oudshoorn, 2011). We performed pooled multivariate Poisson regression analysis per SO to investigate which personal characteristics impacted the decrease in attendance between 2014 and 2018.

### 2.5.2. Organisational factors

We used IBM SPSS Statistics for Windows v25 to calculate multivariate Poisson regression per SO to investigate whether the inviting organisation impacted the decrease in attendance between 2014 and 2018.

## 2.6. Data availability

Results of this study are based on our own calculations on publically available data from CBS (dataset name: “Erasmus\_MC\_BVO\_2014\_2018\_V1\_DEF.sav”). This is available upon request to CBS (microdata@cbs.nl). Data from PALGA is available upon request after approval by the Scientific Committee of PALGA. Data from ScreenIT/CIS is available upon request from the Dutch SO’s.

## 2.7. Ethical approval

The Medical Ethics Committee of Erasmus MC University Medical Center reviewed the protocol for the linkage of PALGA with CBS and confirmed that it was not subject to the *Medical Research Involving Human Subjects Act* in the Netherlands and, therefore, exempt from ethics approval (MEC-2019-0672). All data owners gave approval for the use of their data for the purposes of this study in compliance with GDPR.

## 3. Results

### 3.1. Attendance trends and descriptives

Table 1 show descriptives by SO for personal characteristics by attendance status. Compared to non-attenders, the cohort of attenders had a higher proportion of women who were Dutch (from 73% in SO 4 to 90% in SO 2), were employed (from 76% in SO 4 to 79% in SO 1) and were in the highest income bracket (from 29% in SO 2 to 41% in SO 1)

Fig. 3 shows attendance rates by SO, year of eligibility for invitation and data source. For all SO’s, there has been a decline in participation in the screening programme from 2014 to 2015 to 2017–2018. In each SO, the attendance rates are lower calculated in the PALGA/CBS dataset than in the ScreenIT/CIS data. The largest drop in attendance rate was seen in SO 3, dropping from 67.0% in 2014–2015 to 58.6% in 2017–2018 (using PALGA/CBS data). Calculating attendance rates in ScreenIT/CIS resulted in higher attendance in all SO’s across all years, mainly due to a lower number of non-attenders in ScreenIT/CIS

(Fig. A1).

Supplementary Figs. A2 to A8 show attendance rates by personal characteristics and inviting organisation. The highest attendance rates were amongst women who were employed (Fig. A4; 60.8%), married (Fig. A6; 62.9%), Dutch (Fig. A7; 61.2%), in the highest income bracket (Fig. A5; 63.4%) or living in households with four persons (Fig. A3; 65.3%). Attendance rates were significantly higher amongst women who were invited by their GP than women invited by their SO (Fig. A8; 69.8%).

## 3.2. Factors affecting attendance

### 3.2.1. Population characteristics (PALGA/CBS data)

Table 2 shows the results of Poisson regression analysis for attendance using PALGA/CBS data, by year of eligibility for invitation, unadjusted and adjusted for population characteristics. In the unadjusted models, the relative risk (RR) of participation in the screening programme was significantly lower in all five SO’s in 2016 and 2017–2018 compared with 2014–2015. Following adjustment, there was almost no change in the RR of participation for any of the five SO’s; that is, all RRs were still significantly lower in 2016 and 2017–2018 compared with 2014–2015. RRs of attendance compared to 2014–2015 were lowest in SO 3 (2016: RR 0.909 (95% CI: 0.901–0.917); 2017–2018: RR 0.876 (95% CI: 0.870–0.883)).

Supplementary Tables A3 to A7 show the RR of attendance for each of the population characteristic included in our analysis. Factors affecting attendance followed similar patterns across all SO’s. Women aged 35 years and older had a significantly higher RR of attendance than women aged 30 years. Compared to women who were Dutch, all other migration background groups had a lower RR of attendance. Following adjustment, only married women had a significantly higher RR of attendance compared to women who were the main breadwinner without a partner, with the exception of SO’s 1 and 5, in which the increased risk was non-significant.

### 3.2.2. Organisational factors (ScreenIT/CIS)

Table 3 shows the results of Poisson regression analysis for attendance using ScreenIT/CIS data, by year of eligibility for invitation, unadjusted and adjusted for inviting organisation. In the unadjusted models, the RR of participation in the screening programme was significantly lower in all five SO’s in 2016 and 2017–2018 compared with 2014–2015. Following adjustment for inviting organisation (either SO or GP), there was no significant difference between the RR of participation in SO 1 for participation in 2017–2018 (RR 0.997 (95% CI: 0.990–1.003)) and in SO 4 for participation in 2016 (RR 0.998 (95% CI: 0.990–1.007)). Following adjustment, the RR of participation was higher in 2016 compared to 2014–2015 in both SO 1 (RR 1.028 (95% CI: 1.020–1.035)) and SO 5 (RR 1.034 (95% CI: 1.026–1.043)).

## 4. Discussion

Our aim was to investigate which factors influence attendance, and which factors have influenced the decrease in attendance between 2014 and 2018. Cessing the use of self-inviting general practices appears to have had an impact on attendance. Following adjustment for inviting organisation, RRs moved closer to 1 in all SO’s. The importance of GP invitations in the Dutch screening programme has been previously observed; Tacken and colleagues found that the odds of attendance in a Dutch population increased when invitations and reminders were sent by a woman’s GP (OR compared to SO invitation: 1.73 (95% CI: 1.15–2.60)) (Tacken et al., 2007). Greater involvement by GPs in the cervical screening programme was previously shown to increase attendance rates (Kant et al., 1997) and compliance with follow-up advice (Palm et al., 1997). The effect of having an invitation sent by the GP has been shown to have a greater impact in groups that have lower attendance rates, such as young women, women with a migration background

**Table 1**  
Distribution of co-variates by attendance status and screening organisations, the Netherlands, 2014–2018.

	SO 1			SO 2			SO 3			SO 4			SO 5		
	Attendees	Non-attendees	p												
<i>Data source</i>															
N in PALGA/CBS	576,273	471,169		220,782	160,713		450,647	270,793		490,133	423,928		489,713	338,025	
N in ScreenIT/CIS	596,872	458,395		226,592	141,533		453,994	248,417		511,482	399,388		502,588	297,002	
<i>Inviting organisation*</i>															
Screening organisation	85.4%	90.4%	<0.01	97.7%	98.7%	<0.01	71.3%	81.9%	<0.01	80.6%	87.7%	<0.01	83.9%	88.3%	<0.01
Self-inviting GP practice	14.6%	9.6%		2.3%	1.3%		28.7%	18.1%		19.4%	12.3%		16.1%	11.7%	
<i>Invitation age</i>															
30 years	11.9%	17.5%	<0.01	10.1%	14.7%	<0.01	10.5%	15.0%	<0.01	11.2%	17.0%	<0.01	10.1%	15.0%	<0.01
35 years	12.3%	15.4%		11.3%	12.5%		11.8%	12.8%		12.4%	14.7%		11.4%	12.6%	
40 years	13.8%	12.8%		12.9%	11.6%		13.2%	11.8%		13.6%	12.7%		12.8%	11.2%	
45 years	16.8%	13.9%		16.6%	14.6%		16.8%	14.2%		16.6%	14.0%		16.3%	13.9%	
50 years	16.8%	13.8%		17.4%	15.2%		17.5%	14.8%		17.0%	13.7%		17.7%	15.2%	
55 years	15.6%	13.5%		16.9%	15.4%		16.4%	15.5%		16.0%	14.0%		17.3%	15.8%	
60 years	12.8%	13.1%		14.8%	16.0%		13.8%	15.9%		13.3%	13.8%		14.3%	16.3%	
<i>Migration background</i>															
Dutch	75.3%	60.7%	<0.01	90.1%	85.7%	<0.01	86.6%	79.6%	<0.01	73.4%	58.7%	<0.01	84.3%	74.0%	<0.01
Non-western, first generation	11.0%	18.6%		3.3%	5.3%		5.2%	8.2%		13.1%	20.0%		5.5%	9.0%	
Non-western, second generation	2.8%	5.3%		0.6%	1.0%		1.0%	2.1%		2.8%	5.6%		1.0%	2.2%	
Western, first generation	5.4%	9.9%		2.8%	4.3%		3.0%	5.2%		5.6%	10.6%		4.4%	9.1%	
Western, second generation	5.5%	5.5%		3.2%	3.7%		4.2%	4.9%		5.0%	5.1%		4.9%	5.8%	
<i>Socio-economic status (based on income source)</i>															
Employed	78.5%	68.1%	<0.01	76.6%	66.3%	<0.01	77.8%	67.3%	<0.01	76.3%	65.2%	<0.01	77.7%	66.8%	<0.01
Not employed, social welfare	13.7%	20.4%		14.0%	22.2%		13.2%	21.2%		13.8%	21.2%		13.6%	21.8%	
Not employed, in education	0.4%	0.7%		0.4%	0.8%		0.3%	0.5%		0.4%	0.8%		0.2%	0.4%	
No income	7.4%	10.8%		9.0%	10.8%		8.8%	11.0%		9.5%	12.7%		8.5%	11.0%	
<i>Number of people in the household</i>															
One person	14.0%	20.1%	<0.01	10.7%	17.4%	<0.01	9.4%	16.9%	<0.01	12.2%	19.1%	<0.01	9.6%	16.3%	<0.01
Two people	28.7%	29.9%		30.6%	31.9%		28.1%	30.8%		29.2%	30.6%		30.2%	33.3%	
Three people	20.8%	20.4%		20.3%	20.1%		20.7%	20.3%		22.0%	21.0%		21.8%	21.5%	
Four people	26.4%	19.2%		27.4%	20.3%		29.0%	20.5%		26.0%	18.7%		28.5%	19.9%	
Five people	7.9%	7.0%		8.7%	7.3%		9.8%	7.8%		8.0%	7.0%		8.0%	6.4%	
Six or more people	2.1%	3.5%		2.2%	3.0%		3.0%	3.7%		2.5%	3.7%		1.9%	2.6%	
<i>Standardised income percentile</i>															
1–24%	14.2%	23.5%	<0.01	16.9%	25.3%	<0.01	14.5%	22.8%	<0.01	15.7%	25.8%	<0.01	13.6%	22.6%	<0.01
25–49%	17.6%	19.0%		23.4%	23.7%		21.6%	22.0%		18.3%	19.7%		19.4%	20.8%	
50–74%	26.8%	23.0%		30.0%	25.4%		30.1%	25.8%		27.0%	23.0%		29.9%	25.7%	
75–100%	40.9%	31.5%		29.1%	22.9%		33.2%	26.5%		38.4%	28.4%		36.6%	28.2%	
Missing	0.6%	2.9%		0.6%	2.7%		0.5%	2.9%		0.6%	3.2%		0.5%	2.8%	
<i>Position in the household</i>															
Breadwinner without partner	24.5%	32.0%	<0.01	19.2%	27.4%	<0.01	17.1%	25.9%	<0.01	22.9%	31.9%	<0.01	17.8%	26.2%	<0.01
Breadwinner with partner	15.4%	14.6%		14.9%	14.0%		13.2%	12.8%		13.3%	13.0%		13.0%	12.9%	
Married partner	44.7%	35.9%		51.3%	41.9%		55.5%	44.7%		50.1%	38.9%		53.9%	43.2%	
Unmarried partner	13.7%	13.4%		13.3%	13.7%		12.5%	12.7%		12.0%	12.0%		13.5%	13.8%	
Adult child	0.9%	2.2%		0.7%	1.8%		0.9%	2.4%		0.9%	2.2%		1.0%	2.3%	
Other household member	0.9%	2.1%		0.6%	1.3%		0.8%	1.6%		0.8%	1.9%		0.8%	1.6%	

\*Data from ScreenIT/CIS.

NB: Proportions are rounded to one decimal place and, therefore, may not sum to 100%.

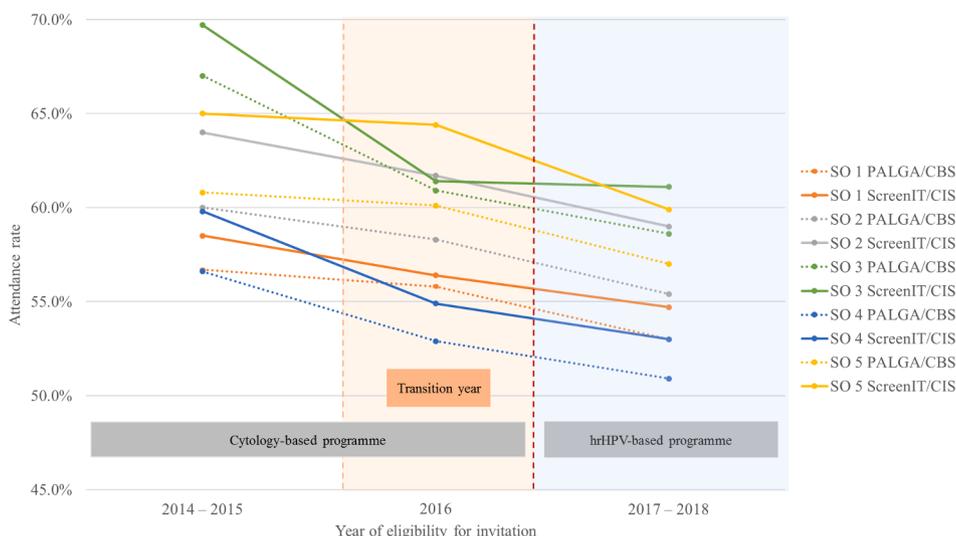


Fig. 3. Attendance rates by screening organisation, year of eligibility for invitation and data source, the Netherlands, 2014–2018.

Table 2

Results of Poisson regression analysis for attendance using PALGA/CBS data, by year of eligibility for invitation, unadjusted and adjusted for population characteristics, the Netherlands, 2014–2018.

	Unadjusted model	Adjusted models		
	Model 1 <sup>1</sup>	Model 2 <sup>2</sup>	Model 3 <sup>3</sup>	Model 4 <sup>4</sup>
	RR (95% CI)	RR (95% CI)	RR (95% CI)	RR (95% CI)
<b>SO 1</b>				
2014–2015	1.000 (ref)	1.000 (ref)	1.000 (ref)	1.000 (ref)
2016	0.985 (0.978–0.992)	0.988 (0.981–0.995)	0.987 (0.980–0.994)	0.988 (0.981–0.995)
2017–2018	0.931 (0.926–0.937)	0.940 (0.934–0.945)	0.944 (0.938–0.950)	0.944 (0.938–0.950)
<b>SO 2</b>				
2014–2015	1.000 (ref)	1.000 (ref)	1.000 (ref)	1.000 (ref)
2016	0.971 (0.960–0.982)	0.971 (0.960–0.983)	0.971 (0.959–0.982)	0.971 (0.960–0.982)
2017–2018	0.922 (0.912–0.931)	0.924 (0.914–0.933)	0.926 (0.916–0.935)	0.926 (0.916–0.935)
<b>SO 3</b>				
2014–2015	1.000 (ref)	1.000 (ref)	1.000 (ref)	1.000 (ref)
2016	0.908 (0.901–0.916)	0.909 (0.901–0.917)	0.908 (0.900–0.916)	0.909 (0.901–0.917)
2017–2018	0.873 (0.866–0.879)	0.875 (0.868–0.881)	0.876 (0.869–0.882)	0.876 (0.870–0.883)
<b>SO 4</b>				
2014–2015	1.000 (ref)	1.000 (ref)	1.000 (ref)	1.000 (ref)
2016	0.935 (0.927–0.943)	0.939 (0.931–0.947)	0.938 (0.930–0.946)	0.939 (0.931–0.946)
2017–2018	0.897 (0.891–0.903)	0.906 (0.900–0.913)	0.908 (0.902–0.915)	0.908 (0.902–0.915)
<b>SO 5</b>				
2014–2015	1.000 (ref)	1.000 (ref)	1.000 (ref)	1.000 (ref)
2016	0.988 (0.981–0.996)	0.990 (0.983–0.998)	0.989 (0.981–0.996)	0.989 (0.982–0.997)
2017–2018	0.934 (0.928–0.941)	0.939 (0.933–0.946)	0.941 (0.935–0.947)	0.941 (0.935–0.948)

RR: relative risk; CI: confidence interval.

NB: Estimates are rounded to three decimal places.

<sup>1</sup> Unadjusted model. Year of eligibility for invitation only.

<sup>2</sup> Adjusted model. Year of eligibility for invitation and migration background.

<sup>3</sup> Adjusted model. Year of eligibility for invitation, migration background, socio-economic status (based on income source), number of persons in household, position in household and standardised household income percentile.

<sup>4</sup> Adjusted model. Year of eligibility for invitation, migration background, socio-economic status (based on income source), number of persons in household, position in household, standardised household income percentile and age.

Table 3

Results of Poisson regression analysis for attendance using ScreenIT/CIS data, by year of eligibility for invitation, unadjusted and adjusted for inviting organisation the Netherlands, 2014–2018.

	Unadjusted model	Adjusted model
	Model 1 <sup>1</sup>	Model 2 <sup>2</sup>
	RR (95% CI)	RR (95% CI)
<b>SO 1</b>		
2014–2015	1.000 (ref)	1.000 (ref)
2016	0.964 (0.958–0.971)*	1.028 (1.020–1.035)*
2017–2018	0.935 (0.930–0.941)*	0.997 (0.990–1.003)
<b>SO 2</b>		
2014–2015	1.000 (ref)	1.000 (ref)
2016	0.963 (0.953–0.974)*	0.971 (0.960–0.982)*
2017–2018	0.921 (0.913–0.930)*	0.928 (0.920–0.937)*
<b>SO 3</b>		
2014–2015	1.000 (ref)	1.000 (ref)
2016	0.881 (0.874–0.888)*	0.990 (0.980–1.000)*
2017–2018	0.876 (0.870–0.882)*	0.984 (0.975–0.993)*
<b>SO 4</b>		
2014–2015	1.000 (ref)	1.000 (ref)
2016	0.919 (0.912–0.925)*	0.998 (0.990–1.007)
2017–2018	0.887 (0.881–0.892)*	0.964 (0.957–0.971)*
<b>SO 5</b>		
2014–2015	1.000 (ref)	1.000 (ref)
2016	0.991 (0.984–0.998)*	1.034 (1.026–1.043)*
2017–2018	0.921 (0.915–0.927)*	0.961 (0.954–0.968)*

\* $p < 0.05$ .

NB: Estimates are rounded to three decimal places.

<sup>1</sup> Unadjusted model. Year of eligibility for invitation only.

<sup>2</sup> Adjusted model. Year of eligibility for invitation and inviting organisation.

and women with a lower SES (de Nooijer et al., 2005). The Health Council of the Netherlands advised in 2011, based on findings from an expert committee that included GPs, that more GPs should be involved in the invitation process as this is the most effective method for promoting attendance, especially in particular population subgroups (Health Council of the Netherlands, 2011). The more personal approach of being contacted by a trusted healthcare provider, rather than a government organisation, may have encouraged some women to participate. Re-instating GP invitations may have a positive impact on future attendance.

Results of our study show that, although there are differences between the personal characteristics of attenders and non-attenders, these differences do not explain the decline in attendance. Like in other

organised European screening programmes, attendance in the Dutch programme was lower amongst women with a migration background (Leinonen et al., 2017a, 2017b; Harder et al., 2018; Kristensson et al., 2014), women in lower income brackets (Harder et al., 2018; Broberg et al., 2018) and women who live alone or are not married (Kristensson et al., 2014; Broberg et al., 2018; Virtanen et al., 2015). Addressing disparities in participation across population subgroups is necessary to ensure that screening benefits all eligible women.

Self-sampling has been shown to reduce non-attendance, however, lower participation in the Dutch programme comes in spite of the introduction of self-sampling. This may, in part, be due to the fact that women in the Dutch programme need to order their self-sampling kit via a web portal. Studies have found that sending self-sampling kits directly to non-responders increased participation (Gok et al., 2010; Elfstrom et al., 2019; Giorgi Rossi et al., 2015) and that sending self-sampling kits directly to women has been shown to be more effective at increasing participation than 'opt-in' strategies (Arbyn et al., 2018; Verdoodt et al., 2015; Tranberg et al., 2018). Having to actively obtain a kit has shown mixed results; some studies show that offering the opportunity to order or collect a self-sampling kit results in higher participation (Broberg et al., 2014; Elfstrom et al., 2019) and some studies show no increase compared to standard procedures. (Giorgi Rossi et al., 2015, 2011) Making it easier to order the kit or sending the kit directly to non-responders may improve uptake in the Dutch programme. However, a Danish study found that not all non-attenders respond equally to the offer of self-sampling; non-attending women from lower socio-economic status, with a migration background and who found cervical cancer screening irrelevant to them were all less likely to use self-sampling (Harder et al., 2018).

Despite the difference made to RRs by adjusting for inviting organisation, estimates in all but one SO remained significantly lower in 2017–2018. There are some additional organisational factors that we were unable to control for that may also have impacted attendance. In the old cytology-based programme, smears could be taken by GPs without the invitation letter, meaning that women could be screened by their GP even if they had come to the clinic for another reason; a screen within the programme was registered if it was specified as such on the laboratory form. In the new hrHPV-based programme, screening within the programme is only possible if a woman brings her invitation letter to the GP, as it contains personalised stickers that need to be stuck to the sample vial for lab processing. It could be that more women were screened in the old programme because it was simply easier to have a screen registered as being taken in the programme. The hrHPV test itself may also be a barrier for some women to participate. However, several studies on regional implementation of primary HPV screening have not shown lower attendance in comparison to cytology-based screening (Thomsen et al., 2020; Passamonti et al., 2017; Pasquale et al., 2015; Veijalainen et al., 2019), suggesting that the test itself may not be the reason for decreased attendance.

Our study has several strengths. We have a unique dataset with information about the personal characteristics of both attenders and non-attenders to the screening programme. Our datasets were large and had population-wide coverage. Because of this, we can be certain that our statistical estimates are robust. Our study is also the first to show attendance behaviours in a nationally implemented hrHPV-based cervical screening programme.

Our study also has some limitations. Some non-attenders would be ineligible for screening due to hysterectomy. While hysterectomy information is available in ScreenIT/CIS, we did not use this for adjustment as it is incomplete (only available if a woman reports this to the SO). We were unable to use hysterectomy data to adjust the eligible population in PALGA/CBS due to left-censoring in our PALGA extract and the linkage protocol used (i.e. we only linked primary screening programme screens, not histological examinations). If adjustment was possible, attendance would be slightly higher in all years (due to a smaller denominator). However, it is unlikely that ineligibility due to

hysterectomy has changed over our study period, so we expect this has not impacted our results. The difference between attendance rates between ScreenIT/CIS and PALGA/CBS were due to lower numbers of non-attenders and overall records in ScreenIT/CIS (Fig. A1). The exact reasons for this difference are unclear, but may be due to a lower number of invitations sent than women in the population, due to opt-outs and some women not being at risk, i.e. having no cervix. Socioeconomic status is a combination of factors related to income, education and occupation (Baker, 2014), however, we did not include education level as a covariate. Educational status data was only complete from registry data for a selection of women in our cohort. As such, we chose not to include this information in our study.

## 5. Conclusion

Removing the possibility for GPs to send invitations explains a large part of the decline in participation in the Dutch cervical cancer screening programme, although this did not account for the total change in attendance. While certain population groups had lower attendance rates, personal characteristics of attenders and non-attenders do not explain the decline in participation. Other factors, such as necessitating the invitation letter be taken to the screening appointment or attitudes to hrHPV screening, should be investigated as additional causes for reduced attendance. GP invitations should be reintroduced to increase attendance.

## CRedit authorship contribution statement

**Clare A. Aitken:** Formal analysis, Writing - original draft, Visualization, Project administration, Data curation, Writing - review & editing. **Sylvia Kaljouw:** Formal analysis, Writing - original draft, Visualization, Writing - review & editing. **Albert G. Siebers:** Resources, Data curation, Writing - review & editing. **Matilde Bron:** Resources, Data curation, Writing - review & editing. **Anne Morssink:** Investigation, Project administration, Writing - review & editing. **Folkert J. van Kemenade:** Supervision, Writing - review & editing. **Inge M.C.M. de Kok:** Conceptualization, Supervision, Writing - review & editing.

## Declaration of Competing Interest

The 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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## Contributions to Authorship

CAA and SK contributed equally to this study. IdK was responsible for study design and acquisition of data from CBS with contribution from

CAA. AM obtained and compiled contextual and policy information from the five SO's and was responsible for writing the study protocol for the analysis of the SO data. CAA made requests for PALGA data, with contribution from IdK and FvK. AGS created the PALGA dataset and collaborated with ZorgTTP and CBS to facilitate data linkage. MB was responsible for obtaining, linking and collating ScreenIT/CIS data. MB also provided expert advice on ScreenIT/CIS data definitions. CAA and SK both analysed data; SK performed statistical modelling on PALGA/CBS data and CAA ran statistical models on ScreenIT/CIS data. CAA drafted the original manuscript with significant contribution from SK. All authors critically evaluated the manuscript and provided feedback that was used to write the final version. All authors have read and agreed to the final version of the manuscript.

## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pmedr.2021.101328>.

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