CHAPTER

Reasons for non-attendance to cervical screening and preferences for HPV self-sampling in Dutch women


ABSTRACT

Objectives
High attendance rates in cervical screening are essential for effective cancer prevention. Offering HPV-self-sampling to non-responders increases participation rates. The objectives of this study were to determine why non-responders do not attend regular screening, and why they do or do not participate when offered a self-sampling device.

Methods
A questionnaire study was conducted in the Netherlands from October 2011 to December 2012. A total of 35,477 non-responders were invited to participate in an HPV-self-sampling study; 5347 women did opt-out. Finally, 30,130 women received a questionnaire and self-sampling device.

Results
The analysis was based on 9484 returned questionnaires (31.5%) with a self-sample specimen, and 682 (2.3%) without. Among women who returned both, the main reason for non-attendance to cervical screening was that they forgot to schedule an appointment (3068; 32.3%). The most important reason to use the self-sampling device was the opportunity to take a sample in their own time-setting (4763; 50.2%). A total of 30.9% of the women who did not use the self-sampling device preferred after all to have a cervical smear taken instead.

Conclusions
Organisational barriers are the main reason for non-attendance in regular cervical screening. Important reasons for non-responders to the regular screening to use a self-sampling device are convenience and self-control.
INTRODUCTION

Screening programmes are only effective if a substantial part of the target population is screened. The coverage of all European cervical screening programmes is below 80%, ranging from 10% to 79%. In only five regions (France, England, Finland, the Netherlands and Sweden) the coverage was 70% or more. Women not participating in the cervical screening programme, called ‘non-responders’, are at increased risk of cervical cancer.

It is commonly assumed that high-risk human papillomavirus (hrHPV) testing on clinician-collected cervical samples provides better protection against cervical cancer than cytology, given its higher sensitivity for detecting cervical intraepithelial neoplasia grade 2 or worse. Therefore, many developed countries will probably convert from cytology to primary HPV testing. Furthermore, hrHPV DNA testing on self-sampled cervicovaginal material (HPV-self-sampling) has similar sensitivity for detecting high-grade CIN as hrHPV DNA testing on clinician-collected material, provided that a combination of a clinically validated self-sampling device and ditto HPV test is used. Offering self-sampling for hrHPV DNA testing has proven to be an effective screening method for women who do not attend regular cervical screening programmes; one third return the self-sampling device, thereby increasing the attendance rate of the screening programme significantly.

The aims of the study were to determine non-responders’ reasons not to attend regular cervical screening, and why these non-responding women do or do not participate when offered a self-sampling device. This study is the first to report on women’s reasons to participate neither in the regular screening programme, nor in a self-sampling programme. This information may provide opportunities to increase screening coverage.

METHODS

In the Netherlands, cervical cancer screening started in the early 1970s. Since the subsequent restructuring of the Dutch screening programme in 1988 and 1996, there has been a nationwide programme targeting women aged 30–60 years. Those women are invited at 5-year intervals for cervical smears, often taken by their general practitioner or practice assistants. The Dutch screening programme has contributed to a reduction in morbidity and mortality of cervical cancer.

This study is a part of a large randomised controlled trial (PRotection by Offering HPV TEsting on Cervicovaginal specimens Trial, PROHTECT 3B) in the setting of the Dutch population-based cervical screening programme. The PROHTECT 3B study assesses the feasibility and efficacy of offering either a cervicovaginal lavage self-sampling device or a brush self-sampling device for hrHPV testing to non-responders of the regular screening programme (1:1 randomisation). Details of this study design are reported elsewhere (Dutch Trial Register, NTR3350).
A total of 35,477 non-responders were selected who lived in the provinces of Noord-Holland, Flevoland, Utrecht or Gelderland and who had received a screening invitation in 2008. The selected non-responders were registered in the databases of the screening organisations. A ‘non-responder’ was defined as a woman who responded neither to the regular invitation to the national screening programme nor to a standard reminder after 6 months. All the selected non-responders received a pre-invitation letter by regular post. Non-responders who did not want to participate could opt out by returning a form by regular post, sending an e-mail, calling a service desk, or opting out via the study website (http://www.thuis-test-hpv.nl). All women who did not opt out within 3 weeks received a self-sampling device with a questionnaire. A total of 5347 women did opt out and 30,130 women received both a self-sampling device and a questionnaire (Figure 1).

For the data collection process Cardiff Teleform Software (version 10.1, 2010; Cambridge, UK) was used. This programme enabled the data manager to scan, verify, and store large quantities of information in an integrated SPSS (Statistical Package for the Social Sciences, version 20.0.1 for Windows) database.

Women could either or not return a self-sampling device, and either or not return a questionnaire. The four outcome-groups are shown in Figure 1. For this questionnaire study, we could calculate only the data for the two groups who returned the questionnaire: non-responding women from the cervical screening programme who participated in the self-sampling study and returned a questionnaire (i.e. group 1, n = 9484) and non-responding women from the cervical screening programme who did not participate in the self-sampling study but did return a questionnaire (i.e. group 3, n = 682).

Each question in the questionnaire contained multiple answer options as well as an open answer
option. Women were allowed to fill in multiple answers. All different answer combinations were analysed and it was calculated whether these combinations changed the results. Open answers were analysed and grouped into categories. Percentages were calculated for each answer option. Categories constituting less than 5% were collected in a rest group.

Table 1. Total amount of women who returned a questionnaire, categorised by age

<table>
<thead>
<tr>
<th>Age category in years</th>
<th>Total amount of women offered an HPV self-sampling device with questionnaire</th>
<th>Participants to self-sampling who returned a questionnaire (%) (group 1)</th>
<th>Non-participants to self-sampling who returned a questionnaire (%) (group 3)</th>
<th>Total amount of women who returned a questionnaire (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>29–33</td>
<td>6526</td>
<td>1916 (29.3)</td>
<td>136 (2.1)</td>
<td>2052 (31.4)</td>
</tr>
<tr>
<td>34–38</td>
<td>6698</td>
<td>2118 (31.6)</td>
<td>115 (1.7)</td>
<td>2233 (33.3)</td>
</tr>
<tr>
<td>39–43</td>
<td>4482</td>
<td>1470 (32.8)</td>
<td>55 (1.2)</td>
<td>1525 (34.0)</td>
</tr>
<tr>
<td>44–48</td>
<td>3832</td>
<td>1216 (31.7)</td>
<td>88 (2.3)</td>
<td>1304 (34.0)</td>
</tr>
<tr>
<td>49–53</td>
<td>3232</td>
<td>1083 (33.5)</td>
<td>98 (3.0)</td>
<td>1181 (36.5)</td>
</tr>
<tr>
<td>54–58</td>
<td>2825</td>
<td>892 (31.6)</td>
<td>71 (2.5)</td>
<td>963 (34.1)</td>
</tr>
<tr>
<td>59–63</td>
<td>2635</td>
<td>789 (29.9)</td>
<td>119 (4.5)</td>
<td>908 (34.4)</td>
</tr>
<tr>
<td>Total</td>
<td>30,130</td>
<td>9484 (31.5)</td>
<td>682 (2.3)</td>
<td>10,166 (33.7)</td>
</tr>
</tbody>
</table>

RESULTS

A total of 10,027 out of 30,130 women (33.3%) returned a self-sampling device, of whom 9484 women also returned a questionnaire (group 1), and 543 only returned a self-sample specimen without a questionnaire (group 2). A total of 20,130 women did not return a self-sampling device, of whom 682 women did return a questionnaire (group 3). These groups are shown in Figure 1. Overall, 10,166 questionnaires were returned. Response rates per age group (groups 1 and 3) are shown in Table 1.

Reasons for non-attendance in the last regular screening round

The main reason for non-attendance in the last regular screening round in both groups was that women forgot to make an appointment for a physician-taken cervical smear. This answer was given by 32.3% of group 1, and 14.2% of group 3 (Table 2).

In the open answer section, 18.2% of the women in group 3, and 11.9% of the women in group 1 answered that they had already had a smear taken in the past 3 years. The second most mentioned open answer in group 1 was that they were pregnant, breastfeeding or in a fertility treatment during the last screening round (8.5%). Furthermore, some women in group 1 felt too years, to
Table 2. Results from the question 'What was/were the reason(s) for not participating in the last regular screening round?'

<table>
<thead>
<tr>
<th>Reason</th>
<th>Total of women who returned a self-sample specimen with a questionnaire (N)</th>
<th>Age category in years (N)</th>
<th>Total of women who returned a questionnaire without a self-sample specimen (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel too embarrassed to have a smear taken (%)</td>
<td>1576 (16.6)</td>
<td>29–33 (1916)</td>
<td>22 (3.2)</td>
</tr>
<tr>
<td>I am afraid to have a smear taken (%)</td>
<td>800 (8.4)</td>
<td>34–38 (2118)</td>
<td>46 (6.7)</td>
</tr>
<tr>
<td>I do not want a cervical smear taken by my own GP (%)</td>
<td>835 (8.8)</td>
<td>39–43 (1470)</td>
<td>13 (1.9)</td>
</tr>
<tr>
<td>I could not make a suitable appointment (%)</td>
<td>928 (9.8)</td>
<td>44–48 (1216)</td>
<td>10 (1.5)</td>
</tr>
<tr>
<td>I forgot to schedule an appointment (%)</td>
<td>3068 (32.3)</td>
<td>49–53 (1083)</td>
<td>97 (14.2)</td>
</tr>
<tr>
<td>I had a previous unpleasant experience with having a smear taken (%)</td>
<td>587 (6.2)</td>
<td>54–58 (892)</td>
<td>22 (3.2)</td>
</tr>
<tr>
<td>I do not participate because of principle reasons (%)</td>
<td>66 (0.7)</td>
<td>59–63 (789)</td>
<td>35 (5.1)</td>
</tr>
<tr>
<td>Filled in an open answer (%)</td>
<td>3852 (40.6)</td>
<td></td>
<td>283 (41.5)</td>
</tr>
</tbody>
</table>

GP = general practitioner

a Women were allowed to indicate multiple answers.

*b Open answers were categorised. Categories constituting less than 5% were collected in a rest group. Categories constituting more than 5% are described in the result section.
Reasons for non-attendance to cervical screening

Embarrassed to have a cervical smear taken by the physician (1576; 16.6%); this number decreased with age. Also anxiety for having a smear taken decreased with age; 12.2% in women aged 29–33 6.1% in women aged 59–63 years. By contrast, previous unpleasant experiences with having a smear taken increased with age (3.1% in women aged 29–33 years to 9.3% in women aged 59–63 years). Among women in group 3, the second most given reason (46; 6.7%) for not participating in the population-based screening was that they were too afraid to have a smear taken. Feelings of embarrassment were scored less often. A single answer was scored in 77.9% of the cases in group 1 and in 90.5% of the cases in group 3. Analysis for multiple answers did not change the results compared to single answers (data not shown).

Participating or not participating in the self-sampling study

A total of 9397 out of 9484 (99.1%) women who returned the self-sampling device and questionnaire (group 1) answered the question about why they used the self-sampling device (Table 3). The most common reason was that it could be done in their own time setting at home (4763; 50.2%). “Performing the self-sampling test takes less effort than having a cervical smear taken” (3982, 42.0%), and “women can perform the self-sampling test themselves” were other important reasons (3478, 36.7%). Younger women more often indicate 1) a reduction in embarrassment, 2) less effort and time investment, and 3) the do-it-yourself aspect as a reason to use the self-sampling device than older women (Table 3).

<table>
<thead>
<tr>
<th>Age category in years</th>
<th>Number of self-sampling responders who returned a questionnaire, per age group</th>
<th>I feel less embarrassment of taking a self-sample (%)</th>
<th>It takes less effort and time than having a cervical smear (%)</th>
<th>I can do it alone and by myself (%)</th>
<th>I can do it in my own time (%)</th>
<th>I am now more aware of the risk of getting cervical cancer (%)</th>
<th>I am less afraid for pain with the self-sample device (%)</th>
<th>Filled in an open answer (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>29–33</td>
<td>1916</td>
<td>499 (26.0)</td>
<td>809 (42.2)</td>
<td>754 (39.4)</td>
<td>907 (47.3)</td>
<td>269 (14.0)</td>
<td>279 (14.6)</td>
<td>339 (17.7)</td>
</tr>
<tr>
<td>34–38</td>
<td>2118</td>
<td>512 (24.2)</td>
<td>968 (45.7)</td>
<td>818 (38.6)</td>
<td>1,089 (51.4)</td>
<td>275 (13.0)</td>
<td>302 (14.3)</td>
<td>357 (16.9)</td>
</tr>
<tr>
<td>39–43</td>
<td>1216</td>
<td>242 (19.9)</td>
<td>510 (41.9)</td>
<td>439 (36.1)</td>
<td>629 (51.7)</td>
<td>137 (11.3)</td>
<td>164 (13.5)</td>
<td>242 (19.9)</td>
</tr>
<tr>
<td>44–48</td>
<td>1470</td>
<td>294 (20.0)</td>
<td>675 (45.9)</td>
<td>553 (37.6)</td>
<td>754 (51.3)</td>
<td>172 (11.7)</td>
<td>177 (12.0)</td>
<td>196 (13.3)</td>
</tr>
<tr>
<td>49–53</td>
<td>1083</td>
<td>199 (18.4)</td>
<td>437 (40.4)</td>
<td>379 (35.0)</td>
<td>565 (52.2)</td>
<td>97 (9.0)</td>
<td>152 (14.0)</td>
<td>191 (17.6)</td>
</tr>
<tr>
<td>54–58</td>
<td>892</td>
<td>147 (6.5)</td>
<td>339 (38.0)</td>
<td>295 (33.1)</td>
<td>455 (51.0)</td>
<td>73 (8.2)</td>
<td>138 (15.5)</td>
<td>137 (15.4)</td>
</tr>
<tr>
<td>59–63</td>
<td>789</td>
<td>102 (12.9)</td>
<td>244 (30.9)</td>
<td>240 (30.4)</td>
<td>364 (46.1)</td>
<td>72 (9.1)</td>
<td>109 (13.8)</td>
<td>150 (19.0)</td>
</tr>
<tr>
<td>Total</td>
<td>9484</td>
<td>1995 (21.0)</td>
<td>3982 (42.0)</td>
<td>3478 (36.7)</td>
<td>4763 (50.2)</td>
<td>1095 (11.5)</td>
<td>1321 (13.9)</td>
<td>1612 (17.0)</td>
</tr>
</tbody>
</table>

* Women were allowed to indicate multiple answers.
Table 4. Results from the question ‘What was/were the reason(s) not to use the self-sampling device?’ (n = 682)*

<table>
<thead>
<tr>
<th>Reason</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I prefer a smear and would like an invitation for the regular screening</td>
<td>211 (30.9)</td>
</tr>
<tr>
<td>I do not want to participate (no special reason)</td>
<td>123 (18.0)</td>
</tr>
<tr>
<td>I am pregnant</td>
<td>62 (9.1)</td>
</tr>
<tr>
<td>I had a hysterectomy</td>
<td>38 (5.6)</td>
</tr>
<tr>
<td>Filled in an open answer</td>
<td></td>
</tr>
<tr>
<td>I already had a cervical smear taken in the past 3 years</td>
<td>142 (20.8)</td>
</tr>
<tr>
<td>Otherb</td>
<td>129 (18.9)</td>
</tr>
</tbody>
</table>

*a Women were allowed to indicate multiple answers.

*b Open answers were categorised. Categories constituting less than 5% percent were collected in a rest group.

The women who did not return a self-sampling device were asked why they had not used the self-sampling device (Table 4). Most women who returned a questionnaire (211 out of 682; 30.9%) indicated that they preferred an invitation to have a regular cervical smear taken, whereas 123 women (18.0%) gave no specific reason for their non-attendance in the self-sampling study.

Almost half of the women in group 1 (48.9%) selected one answer, whereas, of the women in group 3, 76.4% selected one answer. Analysis for multiple answers in both groups did not change the results compared to single answers (data not shown).

DISCUSSION

The main reason for non-attendance in the Dutch regular cervical screening programme, for women who returned the questionnaires, was that women forgot to schedule an appointment to have a cervical smear taken. This was the most given answer for both women who did (group 1) and did not (group 3) return a self-sampling device along with the questionnaire. Furthermore, the women in group 1 felt too embarrassed to have a cervical smear taken by the physician. Among the women in group 3, the second most given reason not to participate in the population-based screening was that they were too afraid to have a smear taken.

In a study from the UK with 580 women of whom 86 non-responders for screening showed similar results for non-attendance. Practical barriers, such as difficulty in making an appointment and difficulty to get an appointment to fit in with work and childcare commitments, were found to be more predictive than emotional factors. Emotional barriers, a previous negative experience, and dissatisfaction with their general practitioner were identified as other important reasons for women not to attend cervical screening. In our data these reasons were only reported in a minority of cases. Explanations for the different reasons to non-attendance might be another
Reasons for non-attendance to cervical screening

Reasons for non-attendance to cervical screening

study design (interviews by phone), smaller number of participants, cultural differences, and age ranges other than the Dutch screening (30–60 years). Additionally, emotional barriers may be found more in women who participated neither in screening nor in self-sampling, and who did not return a questionnaire either (n = 19,421; group 4).

Recently, to increase the participation rate, the Dutch Minister of Health recently decided to reshape the screening programme. Starting from 2016, instead of the regional screening organisations, the general practitioner will be the one to send an invitation for screening together with a date and time based on previous reports from literature. For women it is an extra barrier if they have to make an appointment themselves for an unpleasant test. It is known that an invitation by the general practitioner leads to a slightly higher participation rate compared to an invitation sent by a national or regional organisation. Organising more flexible general practitioner office hours may further lower the threshold for participation; however, the effect of this type of intervention has not been studied yet. Finally, sending a reminder invitation sooner after the regular invitation, sending reminder letters more frequently or phoning the non-responders might also increase participation.

Another approach to lower the threshold for participation that will be introduced in the Dutch screening programme in 2016, is to offer HPV-self-sampling to non-participants of regular screening. Several studies compared two methods for improving attendance rates and concluded that offering self-sampling significantly increases the attendance to the cervical screening programme compared to sending another reminder invitation.

Indeed, the main reason to perform HPV-self-sampling for the self-sampling responders in the current study was that they could do it in their own time and it was less time consuming than having a cervical smear taken. In an Italian study by Giorgi Rossi et al. the main reason was the do-it-yourself opportunity, whereas in the current study this was the third most common answer. Altogether, these results show that self-control and time efficiency are the most important reasons for Dutch non-responders to use a self-sampling device. This seems to apply mostly to the younger women, as they mention those reasons more often, as well as embarrassment and anxiety for having a smear taken. Thus, younger women might benefit more from the introduction of HPV self-sampling in a national screening programme, especially since non-participation is more common in younger women.

The strength of this study is the large cohort of 30,130 women, which is broadly representative of the general Dutch population. To our knowledge, this is the largest survey carried out in a population based screening cohort of non-responding women described in literature so far. From previous research it goes that non-responders to the regular screening program respond in about 30% when offered a self-sampling device. The return rate of self-sampling devices in our study was indeed 33.3% (10,027 out of 30,130). Out of the 10,027 women who returned the self-sampling device, 9484 women also returned a questionnaire. This representative part (94.6%) is a solid basis to pronounce upon this group of self-sampling responders as a whole.
Additionally, this study is the first to report on women’s reasons to participate neither in the regular screening programme, nor in a self-sampling programme. Because of their reluctance to participate in any programme or study, reasons for non-participation in this specific subgroup are hard to study. We reported a low response rate for this subgroup in our study (682 out of 30,130, 2.3%). Therefore, the results in this subgroup have to be interpreted with caution, and cannot be generalised for all 20,103 women who did not respond at all. However, since this is the first time this information is reported, the report of these results does provide first insights in women’s motives and gives an impetus to further research on this subject.

Remarkably, one third of the women who did not participate in the self-sampling study, but did return a questionnaire indicates their preference to a cervical smear and would like to receive another invitation for regular screening. One third of these women who prefer an invitation for regular screening were pregnant or breastfeeding or already had a smear taken in 2008. Another explanation why these women prefer a cervical smear might be that women lack confidence to perform the test correctly, as described before in the literature,35,36 or lack confidence in the self-sampling device itself. Furthermore, the wording of the invitation to the self-sampling study might have made them more aware of the importance of screening.

The results of this study most of all pronounce on the women who responded to the self-sampling study by returning a self-sample and/or questionnaire. They may not be generalised offhand to all non-responders to cervical screening (n = 35,477); especially since we have no information on the women who opted out (n = 5347), and the majority of invited women did not respond at all (n = 19,421, group 4). Another weakness of this study is the poor registration of opportunistic screening in the database of the regional screening organisations. For this study we selected non-responders of the screening programme in 2008. At least 12.8% ((1130+124) / 10,166) of the women who returned a questionnaire already had a smear taken in the last 3 years (Table 2). This percentage might be an underestimation, because this answer was only given as an open answer.

In conclusion, this study shows that among women who returned the questionnaire, organisational barriers are the main reasons for non-attendance in the cervical screening programme; emotional arguments appeared to be less important. Important reasons for women who did use a self-sampling device are convenience and self-control. To further improve cervical screening efficacy, special attention should be paid to the group of women who forgot to get a cervical smear taken. Small interventions in the regular screening programme as well as offering self-collection devices to non-responders might partly resolve the organisational barriers and therefore might increase attendance rates in cervical screening.
Appendix: Questionnaire

1. Did you perform the HPV-self-sampling?
   • Yes, proceed to question 2 and 3
   • No, proceed to question 3 and 4

2. What were the most important reasons to use the self-sampling device? (multiple answers allowed)
   • I feel less embarrassed of taking a self-sample than having a cervical smear taken at my general practitioner
   • It takes less effort and time than having a cervical smear.
   • I can do it alone and by myself instead of the general practitioner or assistant
   • I can do it in my own time
   • I am now more aware of the risk of getting cervical cancer
   • I am less afraid for pain with the self-sample device
   • Open answer

3. What was the reasons for non-participation in the last regular screening round for cervical cancer? (multiple answers allowed)
   • I feel too embarrassed to have a smear taken by my general practitioner
   • I am afraid to have a smear taken
   • I do not want a cervical smear taken by my own general practitioner
   • I could not make a suitable appointment
   • I forgot to schedule an appointment
   • I had a previous unpleasant experience with having a smear taken
   • I do not participate because of principle reasons
   • Open answer

4. What was the reason not to use the self-sampling device? (multiple answers allowed)
   • I had a hysterectomy
   • I am pregnant
   • I do not want to participate (no special reason)
   • I prefer a smear and would like an invitation for the regular cervical screening
   • Open answer
REFERENCES


