

# What benefits and harms are important for a decision about cervical screening? A study of the perspective of different subgroups of women

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**Background:** In cervical screening programs, women typically receive information leaflets to support their decision about participation. However, these leaflets are often based on what experts consider important benefits and harms of screening and not what women themselves consider important to know.

**Objective:** To identify which benefits and harms women consider important for making a decision about cervical screening.

**Design:** Cross-sectional study.

**Setting and participants:** Women from the Dutch target group of cervical screening (N=248; 30–60 years), recruited through an online access panel.

**Main variables studied:** Perceived importance of different benefits and harms of cervical screening, assessed through two rating items (“How important is the information about [this harm/benefit] for your decision?” and “For me it is a [benefit/harm] that participating in the screening program leads to [the benefit/harm]”), and one ranking item (“Rank the information according to their importance for your own choice”).

**Results:** Women overall considered the benefits of cervical screening more important than the harms or disadvantages. The most important harm according to women was the chance of false positive results (M=4.88; SD=1.75). Differences between those with lower and higher numeracy/health literacy were found regarding several aspects, e.g. for the chance of false positive results, the chance of false negative results, the chance of overtreatment.

**Discussion and conclusion:** The results suggest that leaflets could include more explicit information about false positive results.

**Keywords:** informed decision making, cervical screening, risk communication, lay perspective

## Introduction

In many western countries, women are invited to participate in a national cervical screening program that involves getting a smear taken (Pap- or HPV (Human Papilloma Virus)-testing)<sup>1–3</sup>. Pap- and HPV testing are methods of detecting abnormalities which might put women at risk of cervical cancer. These screening programs have been shown to be effective in reducing the incidence of cervical cancers and cervical cancer-related deaths.<sup>4,5</sup> Although the benefits of cervical screening outweigh the harms on a population level, this may not be true for each individual woman. As a result, it is increasingly considered important that women become aware of potential harms/disadvantages associated with screening and that

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they make an informed decision.<sup>6</sup> Information leaflets are thus often attached to the invitation and women are usually also provided with a web address for more extended information.<sup>7</sup>

According to experts in the field of informed decision making, leaflets should contain complete and evidence-based benefit/harm information.<sup>8,9</sup> For cervical screening, important benefits are a reduced risk of developing cervical cancer and a reduced risk of cervical cancer-related death.<sup>4,5,10</sup> Potential harms or disadvantages of screening include the chance of a false positive test result, possibly leading to psychological distress,<sup>11</sup> and the chance of overtreatment, with associated risks of premature births and miscarriages.<sup>12,13</sup> A false negative result may also occur, and there may be additional disadvantages of participating in screening, such as costs of further testing after an abnormal test result, and the fact that getting a smear taken can be associated with discomfort, pain, inconvenience or embarrassment.<sup>14,15</sup>

An important question is what benefit/harm information should be communicated in leaflets in order to support the target audience's decisions, because in practice, it is often not feasible to provide all information to avoid information overload. Leaflets already contain much other relevant information, for example about how cervical cancer develops and about the procedure of the screening test. Not only are there quite a number of harms and benefits one could weigh, making the decision making process complex, but these aspects also involve probabilities, such as the risk of cervical cancer or the risks of false positive and false negative test results. In practice, this question is usually resolved by letting screening experts decide on the most essential information to be provided. A recent evaluation of cervical screening leaflets in Scandinavian and English-speaking countries showed that most leaflets provide limited information on potential harms of screening.<sup>16</sup> Current practice thus seems to result in a narrow overview of benefits and harms. It is unknown whether the selected information is actually the most important information in the perspective of women themselves. Presenting only the most decision-relevant information from the target group's perspective is however important, to match information to their needs and to motivate them to act on the information.<sup>17,18</sup>

Until now, women's information needs as to cervical screening have been understudied. Leaflets are often user-tested among the target population, but these leaflets typically consist of items selected beforehand. In addition, an

important question is whether there are differences between subgroups of women<sup>19</sup> and what this means for targeted/tailored information provision (also see<sup>20</sup>). Benefits and harms of cervical screening may not be perceived in the same way, or considered equally important by all groups of women. For example, the risks associated with overtreatment, such as a higher risk of getting a miscarriage or premature birth,<sup>13</sup> are likely to be more important for younger women who still have a wish to have children than for relatively older women.<sup>20</sup> Because age is an important risk factor for cervical cancer, older women in the target group have a higher cervical cancer risk in general, and screening may therefore be more beneficial to them.<sup>10</sup> A recent review on older women's decisions to participate in cervical screening suggested that reassurance but also embarrassment and perceived logistic aspects were important for older women.<sup>20</sup>

Women with relatively low numeracy or health literacy may also perceive benefits and harms differently than those with higher skills, and perhaps especially those aspects that involve probability information. It is known that people with lower literacy and numeracy skills can perceive risks differently than those with higher skills, and also seem to be more vulnerable for the influence of contextual cues in forming their risk perception.<sup>21</sup> People with lower health literacy as well as those with lower numeracy also tend to have less knowledge about screening and health conditions in general (eg,<sup>22-24</sup>) which may impact the value attached to a number of aspects. This may concern both "difficult" aspects such as the chances of false positive and false negative test results,<sup>25</sup> but also more practical or emotional aspects related to screening such as the inconvenience of the tests involved.<sup>26,27</sup> In the context of colorectal cancer screening, for example, Smith and colleagues have reported that people with lower cognitive skills (i.e. numeracy and educational level) are less knowledgeable and less positive about this screening, and also perceive more emotional and practical barriers.<sup>23,27</sup> Also for cervical screening, there is some research showing that women from lower SES (Socio-Economic Status) backgrounds have different perceptions and beliefs than those from higher social classes,<sup>28</sup> but it is unknown how such subgroups actually value the different benefits and harms directly related to screening.

This study aimed to identify which benefits and harms women consider important for making a decision concerning cervical screening, in an attempt to provide suggestions

for improvement of the content of leaflets that are aimed to support informed decision-making of women. We also studied the differences between the following subgroups of women: women of different age groups; women with high educational level versus low educational level; women with high levels of numeracy skills versus low levels of numeracy skills; and women with low levels of health literacy skills versus high levels of health literacy skills.

## Methods

The present study was a cross-sectional study using a questionnaire among women in the target group of the Dutch national cervical screening program. This program invites women between 30 and 60 years old to participate in cervical screening. At the time of the present study, the Dutch screening program involved getting a Pap smear taken at the GP (General Practitioner; cytology only, no HPV testing). The study was exempted from review by a medical research ethics committee in accordance with local regulatory guidelines and standards for human subjects' protection in the Netherlands (Medical Research Involving Human Subjects Act (WMO), 2005).

## Participants

Participants were recruited via a Dutch online access research panel (FlyCatcher Internet Research, 20,000 panel members in total, ISO 20252- and ISO 26362-certified). Members of the Flycatcher Panel register voluntarily by means of a 'double-active-opt-in' approach. They give explicit consent to be included in the panel. Participation in any survey is completely voluntary and panel members may terminate their panel membership at any time. We invited 538 women between the ages of 30 and 60 years old. Women were ineligible if they had ever had surgery where part of their cervix had been removed. We oversampled low educated women because we wanted to ensure enough women in our sample with relatively low socioeconomic status (SES), health literacy and numeracy. The initial response rate was 55.8% (N=300), but several cases were deleted because participants were either not eligible (N=19), their responses were of bad quality (N=4; these participants either gave the same answer on all questions or they answered the questions too fast to be able to have read them), or because participants did not complete the entire questionnaire (N=29), leading to a final response rate of 46.1% (N=248).

## Procedure

Participants read a general study introduction, and were then asked about their screening intentions and perception of the severity of cervical cancer (see variables). These questions were posed to be able to characterize the sample in terms of screening before being exposed to potentially novel information. Next, participants read some minimal background information about the Dutch cervical screening program, about human papilloma virus (HPV) and the relation with cervical cancer, about what the screening program entails, and the implications of the possible screening outcomes. Additionally, they saw an image illustrating the process of HPV developing into cervical cancer. All this information was based on the content of the leaflet of the national cervical screening program of the Dutch National Institute for Public Health and the Environment (RIVM) at the time of our study. After reading the background information, participants were provided with instructions, where we emphasized that we wanted to know their personal opinions and not what they thought other women would think.

Subsequently, participants were provided with the following two pieces of information, which was information that was not provided as such in the then existing leaflet:

1. A fact box about benefits and harms of cervical screening expressed through numerical information (see [Figure 1](#)).
2. A fact box about additional benefits and harms of cervical screening not expressed through numerical information (see [Figure 1](#)).

After seeing each fact box, participants viewed each benefit and harm separately and were provided with items about the importance of these benefits and harms (see variables). Finally, questions about socio-demographic variables, health literacy and numeracy were posed and participants were thanked for participation.

## Materials

Nine benefits and harms were selected in consultation with communication specialists working at the Centre for Population Screening (CvB) of the RIVM, which is the center that coordinates the Dutch cervical screening program. The selection was based on the extended information on the RIVM website at that time as well as on what women from the target group had emphasized in previous qualitative user testing of the CvB (To put this in context:

<b>Cervical screening program</b>		
Screening programme with HPV test among women between 30 and 60 years old. All figures are per 100,000 women; that is approximately the total number of supporters in two big football stadiums.		
	100,000 without screening	100,000 with screening
<b>Benefits</b>		
How many women suffer from cervical cancer?	25	8
How many women die from cervical cancer	8	2
How many women die from another type of cancer	243	243
<b>Harms</b>		
How many healthy women are being referred to the gynaecologist, while later there turns out to be nothing wrong?*	-	1,100
How many women with an abnormal result receive unnecessary treatment?	-	?**
How many women with a reassuring result still develop cervical cancer within five years?	-	5
* This may result in another smear, biopsies and may have psychological impact. You may get anxious.		
** This figure is unknown because it is difficult to determine whether a precursor of cervical cancer actually would have developed into cervical cancer. Therefore it is difficult to determine whether treatment is unnecessary. Treatment involves removing a part of the area between the ectocervix and the endocervical canal. Consequences of the treatment are often blood loss or vaginal secretion. In some cases, treatment may influence future pregnancies, for example by leading to premature birth.		
<b>Cervical screening program</b>		
Screening with an HPV test among women between 30 and 60 years old.		
<b>Benefits</b>		
Participating in the screening programme is free of charge		
Getting a smear taken often does not hurt		
Participating in the screening programme ensures that you know where you stand and can therefore be reassured		
<b>Harms</b>		
Getting a smear taken may be considered unpleasant by some women		
Having the HPV virus may raise questions or lead to worry		
Depending on the deductible of your health care insurance you may have to pay part of or the full costs of further treatment		

**Figure 1** The two presented fact boxes with benefits and harms.

the current leaflet of the Dutch screening program lists only one benefit (reduced risk of getting cervical cancer) and one harm (unnecessary treatment). These aspects are textually described without providing numerical risk information). The following benefits and harms were selected:

- the reduced risk of getting cervical cancer;
- the reduced risk of dying from cervical cancer;
- the chance of an abnormal result, which later turns out to be incorrect (false positive result);
- the chance of unnecessary treatment;
- the chance of a falsely reassuring result (false negative result);
- the costs of the test (consisting of two parts: the initial test is free of charge and follow-up testing may not be free of charge, depending on insurance and deductible);

- the fact that getting a smear taken can be unpleasant;
- the fact that having the HPV virus can lead to questions and worry;
- the fact of knowing where you stand and therefore being reassured.

As can be seen from our selection of benefits and harms, we focused on aspects that can be considered advantages or disadvantages of the screening itself, and not so much on aspects that are known barriers for screening, such as access or distance to screening. We do acknowledge that such factors also influence women's decisions, but these were not considered as direct disadvantages of the screening itself. An exception was made for "costs"; this can be seen as a barrier, but is qualified as a potential disadvantage in the Dutch leaflet.

The first fact box additionally provided the risk of dying from another type of cancer as a comparative anchor value; the second fact box presented getting the smear taken both as a harm (it can be unpleasant) and as a benefit (it usually does not hurt). The first fact box contained numerical probability information displayed in frequencies (X in 100,000, Figure 1), based on fact box design principles.<sup>29–31</sup> The second fact box consisted of benefits and harms not expressed by numbers. Examples of the way the separate benefits and harms were presented are shown in Figure 2 (Figure S1 provides the complete list). These aspects were described in the leaflet through text without providing numerical information.

## Variables

### Items before being exposed to the two fact boxes with benefits and harms

- Screening intentions: “If I were to be invited to participate in the cervical screening program right now, I would participate” (7-point Likert scale from 1 (I would definitely not participate) to 7 (I would definitely participate)).
- Perception of severity of cervical cancer: “Cervical cancer is a ...” (7-point Likert scale from 1 (completely non-severe condition) to 7 (very severe condition)).

### Items about the importance of the benefits and harms after being exposed to the two fact boxes

For each benefit and harm, women were asked to respond to three items:

- “How important is the information about [this harm/benefit] for your decision?” (7-point Likert scale from 1 (very unimportant) to 7 (very important)).
- “For me it is a [benefit/harm] that participating in the screening program leads to [the benefit/harm]” (7-point Likert scale from 1 (totally disagree) to 7 (totally agree)).
- “Rank the following information from parts 1 and 2 of this questionnaire according to their importance for your own choice to participate in the screening program or not. Give the number 1 to the benefit/harm you find the most important, number 2 to the benefit/harm you find the second most important, etc. Give the number 9 to the benefit/harm you find the least important. There are 9 benefits/harms in total.” (Based on these rankings, we calculated the average rankings for all the benefits and harms).

Although the second and third item measured the perceived importance less directly than the first question, we explicitly chose to pose multiple (i.e. three) items, to be able to get a firm idea of the importance attached to different aspects.<sup>32</sup> The ranking question was explicitly added because we expected that participants might give high importance ratings to *all* benefits and harms presented. Ranking more directly forces participants to prioritize aspects.

### Health literacy and numeracy

Health literacy was measured using the NVS-D,<sup>33,34</sup> which measures performance-based health literacy by letting participants read a nutrition label and answering six questions. We

<p><b>2. How many women die from cervical cancer?</b> Of a group of 100,000 who participate in the screening program in each screening round, 2 women die from cervical cancer. Of a group of 100,000 women who do not participate in the screening program, 8 die from cervical cancer.</p> <p>Clarification: Participating in the screening program lowers the chance of dying from cervical cancer.</p>
<p><b>8. Having the HPV virus may raise questions and lead to worry.</b></p> <p>Clarification: If you get the result that you are HPV positive, it may raise questions and lead to worry about your health. Cervical cancer is caused by a long-term infection with the HPV virus. The HPV virus is very common; approximately 80% of women and men will have the virus once in her or his life. The body almost always clears the virus itself, there is no medication for the virus. It is only if the body does not clear the virus that the cells in the cervix may change. The body can also clear these cells. If this does not work, the cells may develop into a precursor of cervical cancer. The HPV virus is transmitted via sexual contact. Using a condom only partially protects against the virus. Infection cannot be prevented. Having many sexual contacts increases the chance of infection with HPV, but this does not work the other way around: having an HPV infection does not mean that someone has had many sexual contacts. Having sex once can be enough to get infected.</p>

**Figure 2** Two of the nine benefits and harms when presented separately with additional explanation.

split the participants into two groups; those who had five or six questions correct (relatively high health literacy) and those who had less than five questions correct (relatively low health literacy). Fransen and colleagues showed that with this cut-off point, 63% of the people with adequate health literacy could be identified and 70% of the people with inadequate health literacy.<sup>34</sup> Numeracy was measured using a one-item version of the Berlin Numeracy (Out of 1,000 people in a small town 500 are members of a choir. Out of these 500 members in the choir 100 are men. Out of the 500 inhabitants that are not in the choir 300 are men. What is the probability that a randomly drawn man is a member of the choir? Please indicate the probability in percent. \_\_\_ %) test. We used a median split, dividing the participants into two groups; relatively low and relatively high numeracy.<sup>35</sup> Participants were allowed to skip the questions about health literacy and numeracy. Women who did so were given a score of 0 and treated as low numeracy/health literacy.

## Analyses

Descriptive analyses were performed to identify which benefits and harms were considered most important. Next, we performed several one-way ANOVAs to study the subgroup differences, with age, education, numeracy and health literacy as the independent variables and the perceived importance score (How important is the information about [this harm/benefit] for your decision?) as the dependent variable. We conducted post hoc tests if the ANOVA revealed significant group differences for age and education (i.e.  $p < .05$ ).

## Results

### Participants' characteristics

Our sample consisted of 248 women between 30 and 60 years old. Table 1 shows their characteristics; their average age was 45.8 years and half of them (51.2%) were low educated. Most participants stated that they would participate in cervical screening if they were to be invited right now; 68.1% stated that they would definitely participate and 13.3% that they would probably do so. In the actual current Dutch cervical screening program, approximately two-thirds of the invited women participate every year.<sup>36</sup> A total of 90.2% of our participants considered cervical cancer to be a severe or very severe condition.

### Importance of the benefits and harms

Table 2 shows the average scores participants gave concerning the perceived importance as well as the extent to

**Table 1** Participants' characteristics. Missing values were not analyzed

Age	N (%)
30–40 years	75 (30.2)
41–50 years	84 (33.9)
51–60 years	89 (35.9)
Education <sup>a</sup>	
Low	127 (51.2)
Intermediate	55 (22.2)
High	66 (26.6)
Numeracy	
Low	114 (46.0)
High	71 (28.6)
(missing)	63 (25.4)
Health literacy	
Low	74 (29.8)
High	135 (54.4)
(missing)	39 (15.7)

**Notes:** <sup>a</sup>Low, intermediate, high; according to the International Standard Classification of Education (ISCED), 2011.

which they perceived the benefits and harms to actually be a benefit or harm. Participants attached most importance to the reduced risk of dying from cervical cancer ( $M=5.37$ ,  $SD=1.79$ ) and the least importance to the fact that getting a smear taken can be unpleasant ( $M=4.35$ ,  $SD=1.86$ ). For the harms, the chance of getting an abnormal result only to find out later that nothing was wrong (i.e. a false positive result) was considered most important ( $M=4.88$ ,  $SD=1.75$ ). In general, participants rated the benefits as being more important than harms; the average importance score over all benefits was 5.05 ( $SD=1.25$ ) whereas for the harms this was 4.55 ( $SD=1.36$ ) (difference  $t(247)=8.01$ ,  $p < .001$ ), although it should be noted that this difference was quite small. Participants also considered the presented benefits to be actual benefits (overall average score  $M=5.63$  ( $SD=1.01$ )) more than they considered the presented harms to be actual harms (overall average score  $M=4.12$  ( $SD=1.13$ )) (difference  $t(247)=15.96$ ,  $p < .001$ ).

The average top 3 (out of 9), resulting from participants' ranking consisted of only benefits (i.e. the reduced risk of getting cervical cancer, the reduced risk of dying from cervical cancer, and the fact that the test result can be reassuring). The highest ranked harm (number 4) was the chance of getting an abnormal result only to find out later that nothing was wrong (i.e. false positive result).

**Table 2** Average importance scores for each benefit and harm, with possible scores ranging from 1 to 7

Benefits	Important for choice M (SD)	Considered as benefit/harm M (SD)	Rank
Reduced risk of getting cervical cancer	5.09 (1.79)	5.26 (1.68)	1
Reduced risk of dying from cervical cancer	5.37 (1.64)	5.80 (1.28)	2
Initial test is free*	4.42 (1.90)	5.53 (1.50)	5
Knowing where you stand and being reassured	5.31 (1.45)	5.92 (1.16)	3
<b>Harms</b>			
Abnormal result, but turns out later that nothing was wrong	4.88 (1.75)	3.87 (1.80)	4
Unnecessary treatment	4.65 (1.62)	3.96 (1.71)	7
Falsely reassuring result	4.43 (1.68)	4.17 (1.64)	6
Follow-up testing may not be free*	4.38 (1.94)	4.63 (1.85)	5
Getting a smear taken can be unpleasant	4.35 (1.86)	3.79 (1.89)	9
Having HPV virus can lead to questions and worry	4.60 (1.77)	4.33 (1.57)	8

**Notes:** \*The costs consisted of two separate parts, both a benefit and a harm.

## Group differences

Table 3 displays all average importance scores among different subgroups. Age groups were not found to differ with regard to perceived importance. Participants with low educational level considered the costs of screening more important than intermediate and highly educated participants ( $F(2,245) = 4.01, p = .019$ ,  $F(2,245) = 7.96, p < .001$ ). Participants with low numeracy considered unnecessary treatment ( $F(1,246) = 6.20, p = .013$ ) and a falsely reassuring result (false negative result) ( $F(1,246) = 11.38, p = .001$ ) more important than those with high numeracy. Furthermore, low numerate participants considered the fact that having the HPV virus can lead to questions and worry also more important ( $F(1,246) = 4.18, p = .042$ ). Similar differences were found between participants with lower health literacy and higher health literacy (see Table 3). For health literacy, we also found differences with regard to the chance of an abnormal test result ( $F(1,246) = 5.43, p = .021$ ), the fact that the initial test is free ( $F(1,246) = 4.01, p = .046$ ), the possible costs of follow-up testing ( $F(1,246) = 10.16, p = .002$ ) and the fact that getting a smear taken can be unpleasant ( $F(1,246) = 8.49, p = .004$ ). In particular, those with relatively low health literacy attached more importance to the costs and that getting a smear taken can be unpleasant compared to those with relatively high health literacy. Given the fact that there was some overlap between findings for numeracy and health literacy, we also assessed the correlation between these measures and this correlation was  $.365 (p < .001)$ .

## Discussion

This study aimed to investigate which benefits and harms women from the target population of cervical screening considered important for making a decision concerning this screening. In doing so, we also studied differences between subgroups of women regarding age, educational level, numeracy and health literacy. Women appeared to attach more importance to a number of benefits compared to the harms, namely: the reduced risk of getting cervical cancer, the reduced risk of dying from cervical cancer, and that they know where they stand and can therefore be reassured by the test result. The harm or disadvantage considered most important was the chance of getting an abnormal test result only to find out later that nothing was wrong (i.e. false positive result). We also demonstrated several subgroup differences in the importance attached to a number of benefits and harms, for example that women with lower numeracy/health literacy considered the chances of unnecessary treatment and a falsely reassuring result (false negative result) more important than women with higher numeracy/health literacy.

Women overall considered the benefits of cervical screening more important than the harms. Related to this, women did not consider most of the harms presented in this study to be actual harms for themselves. This finding corresponds to other studies showing positive attitudes in general towards cervical screening as well as towards other screening programs.<sup>37,38</sup> One could argue that this

**Table 3** Mean perceived importance scores are presented

	Age				Education			Numeracy		Health literacy	
	30–40 years (N=75)	41–50 years (N=84)	51–60 years (N=89)	Low (N=127)	Middle (N=55)	High (N=66)	Low (N=177)	High (N=71)	Low (N=113)	High (N=135)	
<b>Benefits</b>											
Reduced risk of getting cervical cancer	4.96	5.10	5.19	5.13	5.13	4.98	5.20	4.82	5.26	4.95	
Reduced risk of dying from cervical cancer	5.43	5.14	5.53	5.20	5.20	5.27	5.49	5.06	5.44	5.30	
Initial test is free	4.45	4.37	4.44	4.05 <sup>a</sup>	4.05 <sup>a</sup>	4.09 <sup>b</sup>	4.51	4.20	4.68 <sup>a</sup>	4.20 <sup>a</sup>	
Knowing where you stand and being reassured	5.37	5.05	5.51	5.29	5.29	5.26	5.37	5.17	5.36	5.27	
<b>Harms</b>											
Abnormal result, but turns out later that nothing was wrong	4.64	4.79	5.17	4.85	4.85	4.61	4.99	4.61	5.16 <sup>a</sup>	4.64 <sup>a</sup>	
Unnecessary treatment	4.41	4.75	4.76	4.65	4.65	4.50	4.81 <sup>a</sup>	4.25 <sup>a</sup>	4.93 <sup>a</sup>	4.42 <sup>a</sup>	
Falsely reassuring result	4.09	4.62	4.54	4.44	4.44	3.98 <sup>a</sup>	4.66 <sup>a</sup>	3.87 <sup>a</sup>	4.75 <sup>a</sup>	4.16 <sup>a</sup>	
Follow-up testing may not be free	4.09	4.52	4.47	4.09 <sup>a</sup>	4.09 <sup>a</sup>	3.74 <sup>b</sup>	4.49	4.08	4.80 <sup>a</sup>	4.02 <sup>a</sup>	
Getting a smear taken can be unpleasant	4.28	4.31	4.44	4.15	4.15	4.29	4.42	4.15	4.72 <sup>a</sup>	4.04 <sup>a</sup>	
Having HPV virus can lead to questions and worry	4.48	4.57	4.73	4.49	4.49	4.44	4.75 <sup>a</sup>	4.24 <sup>a</sup>	4.77	4.46	

**Notes:** Within each group (age/education/numeracy/health literacy), means with the same superscript (eg. <sup>ab</sup>) in the same row differ significantly ( $p < 0.05$ ). For example, for differences between groups with different educational levels regarding 'initial test is free': a= significant difference between low and middle education; b= significant difference between low and high education.

overall importance attached to screening benefits is not problematic for cervical screening, because the possible harms or disadvantages are considered relatively small compared to, for example, breast cancer screening. When women are properly informed about benefits and harms, it can be argued that it is up to women themselves how they weigh the benefits and harms. However, a positive attitude toward cervical screening and (cancer) screening in general may also be rooted in a common positive societal attitude. Such an attitude may have an unwarranted effect on information processing, for example a positivity bias in information search and in weighing the harms against the benefits. Although cervical screening does actually not test for cancer, but for abnormalities which might put women *at risk* of cervical cancer, the benefits in terms of reduced risk of getting cervical cancer and of dying from cervical cancer will probably play a similar role in decision making as in actual cancer screening. For cancer screening in general, we know that it is not only the general public that is generally positive, but that experts seem to be positive as well.<sup>39</sup> For example, information guidelines for clinicians regarding cancer screening have been shown to be not neutral, lacking information in general (mostly about the harms), or only consisting of non-numerical information.<sup>40</sup> This may mean that even when benefit/harm information is adequately provided to the public, people may not process this information neutrally, but instead focus on positive information. Cervical screening can be harmful to individual women<sup>12,13</sup>. (e.g. unnecessary treatment, anxiety and stress associated with screening and with false positive or false negative results), and we therefore believe that women should be aware of these possible harms/disadvantages when making a decision.

We found a number of differences in perceived importance of benefits and harms between women with lower numeracy/health literacy and women with higher numeracy/literacy. Notably, these differences mostly concerned the harms, including the harms expressed by numerical information, but also some of the benefits. For example, women with lower numeracy/health literacy considered the chance of overtreatment and the chance of a false negative result relatively more important compared to those with higher numeracy/health literacy. It could be that those with lower skills specifically focused on these harms, because they were notable in the accompanying fact box and looked more easy to compare than the numbers relating to the benefits (i.e. there was no comparative information about harms for the option of not

screening). An alternative explanation might be that the numerical fact box was always presented first to participants, and that those with lower skills did not pay much attention to information in the second fact box. Of course it can also be that those with lower numeracy/health literacy actually intrinsically attached more importance to the harms than those with higher skills, from a more negative attitude or skepticism towards screening<sup>23,27</sup> and thus processed the benefit/harm information in light of this. Such differences could be related to the socio-economic position of women with lower numeracy/health literacy, although it should be said that we did not find that much difference between educational levels.

An important finding was that the costs of the screening program were especially important for women with a lower educational level. It makes sense that women with a low educational level consider this more important since they often have less money to spend. It is important to present the information about the costs of screening in such a way that all women can understand it, because information about costs and insurances can be difficult to understand. This may depend on the way screening is financed in different countries. In the Netherlands, the smear in the screening program is free of charge, but further testing may lead to costs, depending on women's health insurance and particularly their deductible.

## Strengths and limitations

To our knowledge, the present study is the first that looks into the perspective of women themselves regarding how much importance they attach to the benefits and harms of cervical screening, including aspects presented through numerical probability information. Our study might be limited by its exploratory nature, which is why we cannot be sure about the reasons why women find particular aspects important and not others. We acknowledge the online lab setting in which our study was performed, which might have biased participants in putting more effort in the information content than what they would normally do at home when receiving a leaflet. However, we do think that the materials used were adequate for our research purposes, as we were interested in how women perceived different potential benefits and harms, which are not all provided in current leaflets.

The way we processed the data about numeracy and health literacy may have led to some bias in our data. Participants were allowed to skip these questions, and, following Cokely et al<sup>35</sup> we considered the missing data as incorrect (i.e. low numeracy and health literacy). Additional analysis showed that women with missing

data on these questions were also more often low educated. It could be that those women were the ones with the lowest levels of health literacy and numeracy, leading to an underestimation of the differences between the low and high skilled groups.

## Practice implications

Our findings suggest that more explicit information about the chances of false positive results could be provided in leaflets about cervical screening. This aspect is not typically given in cervical screening leaflets,<sup>16</sup> while in the present study women considered it to be the most important possible harm or disadvantage of screening. Aspects that seem to be relatively less important to emphasize in information leaflets are the fact that getting a smear taken can be unpleasant and that having the HPV virus can lead to questions and worry. Such information may be referred to in web-based materials.

In our sample, most participants intended to participate in cervical screening and it therefore seems reasonable that they would consider the benefits more important than the harms. Only a few participants stated they would not participate. This is however in line with the actual target population of the Dutch cervical screening program, where approximately two-thirds of the invited women participate every year. It would be interesting to compare women who participate in the screening program to women who do not, to see whether their information needs are different.

An important question remains whether information about benefits and harms should be tailored to different groups of people. Web-based information may offer opportunities to do so. However, based on our findings, we have reason to believe that differences in the perceived importance of information items might be, at least in part, related to differences in how particular subgroups of women understood these items, especially some of the numerical information. Further studies are needed to unravel the mechanisms behind these patterns. Nonetheless, leaflets about cervical screening should at least contain balanced information about the possible benefits and harms. Information about the possible harms is generally more difficult for women to understand because it contains numerical information, very small probabilities and reflects risks that are less concrete or less affective compared to the chance of preventing getting cervical cancer or dying from it. However, not providing those numbers often leads to an even larger overestimation according to previous research<sup>41</sup> and we would therefore not recommend presenting only non-numerical information.

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## Disclosure

The authors declare they have no conflicts of interest.

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## Supplementary material

### 1. How many women get cervical cancer?

Of a group of 100,000 who participate in the screening program in each screening round, 8 women get cervical cancer. Of a group of 100,000 women who do not participate in the screening program, 25 get cervical cancer.

Clarification: If you have cervical cancer or a precursor of cervical cancer, it can be detected early by participating in the screening program. When detected early, cervical cancer can be treated better or even be prevented.

### 2. How many women die from cervical cancer?

Of a group of 100,000 who participate in the screening program in each screening round, 2 women die from cervical cancer. Of a group of 100,000 women who do not participate in the screening program, 8 die from cervical cancer.

Clarification: Participating in the screening program lowers the chance of dying from cervical cancer.

### 3. How many women receive an abnormal test result, while it later turns out that they do not have a precursor of cervical cancer or cervical cancer

Approximately 1,000 of the 100,000 women who participate in the screening program receive the result that an abnormality is found and that further testing by the gynecologist is necessary, while it turns out later that nothing was wrong. There turns out to be no important cell abnormality or cervical cancer.

Clarification: Participating in the screening program can lead to unnecessary anxiety: one gets referred in order to get further tests done, while later it turns out that nothing was wrong. In this case, there is a so-called false positive test result. This result may cause you to worry about your health for a while.

### 4. How many women with an abnormal test result receive unnecessary treatment?

The number of women who receive treatment for a precursor of cervical cancer, while it may not have been necessary, is unknown.

Clarification: A precursor of cervical cancer is almost always treated to be sure, while it may sometimes recover automatically. In that case, treatment was not needed. This is called overtreatment. It cannot be known beforehand whether a precursor of cervical cancer would indeed have led to cervical cancer. This is why numbers about overtreatment are unknown. The treatment involves removing abnormal cells, for example by laser or a small knife. Treatment may lead to blood loss and secretion. In some cases, treatment may influence subsequent pregnancies. It may be more difficult to get pregnant because the cervix produces less mucus. Additionally, there is a higher chance of a premature birth when a large part of the cervix is removed. Finally, childbirth can be more difficult due to possible scar tissue.

### 5. How many women receive the reassuring test result that everything looks normal, while cervical cancer will still develop within 5 years?

Approximately 5 of the 100,000 women who participate in the screening program receive the reassuring test result that everything looks normal, while in fact there turns out to be a precursor of cervical cancer.

Clarification: Just like every other medical examination, the screening program is a snapshot. There is no 100% guarantee that cervical cancer will not develop between two test moments. Women can be falsely assured while they in fact have a precursor of cervical cancer. For these women, the diagnosis was missed. In that case, there is a false negative result.

### 6. Participating in the screening program is free of charge. However, depending on the deductible of your healthcare insurance, you may have to pay for further testing by the gynecologist, either partially or fully.

Clarification: The screening program consists of a smear at the general practice. This smear is free of charge. If you get an abnormal result, you will be recommended to receive further tests by a gynecologist. Approximately 3,600 of the 100,000 women who participate in the screening program will receive a referral to the gynecologist. The costs for these follow-up tests are not part of the screening program. These costs fall under your healthcare insurance. You may therefore have to pay for (a part of) the treatment yourself, this depends on your deductible.

**7. Getting a smear taken is considered unpleasant by some women, but it often does not hurt**

Clarification: The screening program involves getting a smear taken at the general practice. This is often conducted by the doctor's assistant. To get the smear taken you need to take your lower clothes off. You have to lie on the examination table with your legs spread wide. The doctor's assistant will examine you with a special instrument—the speculum. She will carefully insert the speculum into your vagina, to be able to collect mucus from your cervix with a little brush. The speculum will be heated a little with warm water, to make it feel more comfortable. Tell the doctors assistant if you are anxious about getting the smear taken. For example, she may then use a smaller speculum.

**8. Having the HPV virus may raise questions and lead to worry.**

Clarification: If you get the result that you are HPV positive, it may raise questions and lead to worry about your health. Cervical cancer is caused by a long-term infection with the HPV virus. The HPV virus is very common; approximately 80% of women and men will have the virus once in her or his life. The body almost always clears the virus itself, there is no medication for the virus. It is only if the body does not clear the virus that the cells in the cervix may change. The body can also clear these cells. If this does not work, the cells may develop into a precursor of cervical cancer. The HPV virus is transmitted via sexual contact. Using a condom only partially protects against the virus. Infection cannot be prevented. Having many sexual contacts increases the chance of infection with HPV, but this does not work the other way around: having an HPV infection does not mean that someone has had many sexual contacts. Having sex once can be enough to get infected.

**9. Participating in the screening program ensures that you know where you stand and can therefore be reassuring.**

Clarification: On the basis of the test result, you can better determine your risk of developing cervical cancer. If you have a good test result, you are reassured; you are healthy and you do not have to worry a lot about getting cervical cancer before the next screening round. If you get an abnormal test result, you can discuss treatment options with your GP.

**Figure S1** Complete list of the way separate benefits and harms were presented.