

How do women who choose not to participate in population-based cervical cancer screening reason about their decision?

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Abstract

In Stockholm, Sweden, women are invited to a cost-free population-based cervical cancer screening programme (PCCSP) at regular intervals. Despite this, many women choose not to attend screening at all or to take opportunistic tests instead. This study explores how women who actively declined participation in the PCCSP reasoned about their choice. Qualitative telephone interviews and fax messages from women who actively declined participation in the PCCSP were analysed inductively. The manner in which women defined and conceptualized distinctions between, and the roles and responsibilities of, both private and public spheres were found to be central in explanations of decision making. Factors related to women's decisions not to participate in screening at all include a lack of confidence in the benefits of screening, previous negative health care and preventive experiences, a belief in one's own ability to discern health changes or a belief that one was not at risk for cervical cancer, as well as a number of unconventional standpoints on social and political issues. Women who chose not to participate in the organized PCCSP, but who did use private opportunistic screening, generally motivated this with direct or indirect criticism of the screening programme itself. Not only was the examination itself sensitive but also all facets of the PCCSP, from invitation letter on, were found to influence women's decisions. Using Jepson *et al.*'s ethical framework to peruse the evidence-base underlying women's 'informed decision-making' about CCS is suggested to be more constructive than discussing potential participants' knowledge versus lack of knowledge.

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Introduction

Globally, cervical cancer remains the second most common cancer in women [1], despite the existence of the 'Pap smear' to discern cervical cancer in early, non-invasive, asymptomatic stages. Pap smear use in screening programmes has been described as an effective intervention to reduce incidence and mortality from cervical cancer [2]. Cervical cancer screening (CCS) in Sweden differs from that in many other countries as there are population-based cervical cancer screening programmes (PCCSP) [3]. PCCSP in the Stockholm region is coordinated by the regional Oncologic Centre (OC), and is said to have an exemplary organization [3]. Women living in the region receive a letter of invitation to PCCSP every third year between ages 23 and 50 and every fifth year for women aged 51–60.¹ The letter includes information about the test and its aim, appointment

time, and place. Recipients are requested to bring it with them to their Pap test appointment, as the letter also functions as the standardized referral and response form for contact between the PCCSP clinics and the laboratory. It, therefore, also includes classifications for reporting the Pap test results.

The Stockholm region PCCSP Pap smears are taken by midwives at community-based antenatal health clinics (ANHCs). At the time of the present study the Pap smear was cost-free for PCCSP attendees. Women who did not attend their PCCSP appointment without actively informing OC were automatically rebooked for a new appointment three months later.

Sweden is one of three European countries with >80% Pap smear coverage of the target population during the screening interval [4]. Despite this, only 31% of Pap smears registered in 1998 were taken within the PCCSP [5]. Pap smears taken

outside the PCCSP are described as either medically motivated 'indicated' testing or as 'opportunistic' screening. The latter often involves a Pap smear taken at a routine gynaecological check-up by a private gynaecologist [5] and is often seen as problematic due to its lack of control, greater societal cost compared with PCCSP [6], and failure to reach high-risk groups [7].

Women who do not attend CCS have a greater risk of developing cervical cancer [8,9]. As a result, much research in the area focuses on factors influencing CCS attendance and strategies aiming to increase CCS participation. Factors like age, ethnic background, socioeconomic status, education, health insurance, and place of residence have been studied with regard to their relationship to participation in CCS, although results do not always show agreement. For example Maxwell *et al.* [10] found that younger and older Canadian women were less likely to take a Pap smear while Lockwood-Rayermann [11] found that American women of childbearing age (18–44 years) had less CCS participation than older women. Lockwood-Rayermann [11] also found that screening was higher in women without college education, which differs from other international studies finding lower educational levels related to non-participation in CCS [12,13].

A few studies conducted in Sweden on non-participation in PCCSP acknowledge the impact of additional factors. Eaker *et al.* [14] found that factors like non-use of oral contraceptives, contact with several gynaecologists, seeing a physician either very often or not at all, use of condoms, and living in rural areas were associated with non-participation in PCCSP in the Uppsala region. Socioeconomic status or sexual risk behaviour was not associated with non-participation in Eaker *et al.*'s [14] study. Rodvall *et al.* [6] also found no association between socioeconomic status and non-participation in the Stockholm region, while age, marital status, and employment status were related to PCCSP participation.

While knowledge about CCS is reputed to be an important predictor of screening behaviour, results are not always consistent, even in the limited research from Sweden. An early Swedish report [15] indicated that women not participating in screening had less knowledge about screening aims and which type of cancer was tested for than did women participating in the screening. In contrast, 30 years later Eaker *et al.* [14] found that attendees and non-attendees had similar levels of knowledge about the site of cancer screened for, although non-attendees were found to have less knowledge about screening aims and recommended intervals. Idström *et al.* [16] concluded that knowledge about screening was generally low in Swedish women, finding that one of three women in their survey was unaware of which type of cancer was screened for,

although the majority participated in PCCSP. Forss *et al.* [17] used a qualitative approach to study how women described and reasoned about PCCSP participation in Sweden. They found several different ways of reasoning, with only one similar to the biomedical rationale underlying the programme. This study highlighted variations in reasoning about participation, in contrast to research tending to view women as a homogenous group, often assuming a biomedical perspective as norm.

The existing variation even among Swedish studies raises numerous questions about the effects of different methodological approaches as well as how knowledge is conceptualized and instrumentalized in relation to CCS. It also becomes apparent that few recent studies can be found from the perspective of women who choose *not to attend* screening or take a Pap smear. Barriers for taking a Pap smear have been described from different geographic and ethnic groups as including embarrassment, pain and fear of the examination and the result, attitudes and beliefs about the test and the screening procedure, and practical barriers like economic and time factors [18–22]. It should be noted that such findings are generally based on data from women who *have* taken a Pap smear.

Given the importance of CCS for cancer prevention, the absence of research from the perspective of non-participating women is notable, especially in light of the apparent differences between biomedical reasoning and women's conceptualizations of screening, and the lack of consensus about the relevance of specific factors. This study was, therefore, designed to investigate how women who actively choose not to attend the PCCSP in the Stockholm region reason about their choice. This involves investigation of two types of choices: How women reason about participation in opportunistic screening instead of the PCCSP, and how women who have chosen not to undergo CCS at all reason about their decision.

Method

This study derives from a larger multidisciplinary research project with the overall aim of examining PCCSP in the Stockholm region from the perspective of different stakeholders [23]. The study was approved by the relevant research ethics committee (KI dnr 95:89).

Sample and data collection

Women contacting the OC, who neither wished to participate in PCCSP at present nor in the future were the subjects for the study. Data were collected through telephone interviews and fax messages. Women who telephoned OC to decline

participation in PCCSP and who seemed willing to discuss their choices were informed about the study by the OC staff. Women only reporting a motivation fitting one of the OC's predetermined categories, i.e. recent prior Pap test or present contact with a private gynaecologist, were not asked to participate. Written information was sent to those women who expressed interest in the study. A researcher contacted these women by telephone several days later to provide more information and conduct the interview if the woman consented.

Telephone interviews were conducted despite the potential negative features of lacking face-to-face communication [24], to facilitate participation in this hard-to-recruit group. The 10–30-min long telephone interviews were conducted in conversational form and tape recorded in 10 cases. Two women preferred not to have the interview tape recorded; those interviews were instead documented by direct quotes, paraphrases, and a detailed summary by the interviewer. The telephone interviews were conducted by researchers unaffiliated with the PCCSP, primarily author C. T.

At the time of data collection, women who did not participate in PCCSP were asked to return the invitation to the OC with an explanation for their choice. Three predetermined explanations were printed on the invitation, i.e. a test had been taken within the past 18 months, the woman was pregnant, or she resided in a different region. A fourth alternative, 'other explanation' was given a half line of space for a response. All fax messages sent to the OC between 1993 and 2000 using this open alternative were included in the study ($n = 86$).

Data analysis

Analysis was inspired by interpretative description [25,26]. This method is an inductive approach based on the key axioms of naturalistic inquiry [27] to obtain clinically relevant and useful understanding of how people experience issues related to health and illness [25,26].

The database for this analysis consisted of verbatim transcribed, written documentation of telephone interviews and fax messages. After preliminary analysis, interviews and fax messages were analysed together, since the data were highly consistent, although the fax messages tended to be more forcefully expressed.

The first author (K. B.) who was neither involved in data collection nor affiliated with the PCCSP, initially read the interviews and fax messages repeatedly to gain a sense of the data as a whole. Text units with similar meanings were coded together with the help of NVivo software [28]. By moving between the codes and the interviews as a whole, the overall dimension 'Tension between the public and private spheres' was conceptualized.

Themes were distinguished and compared in an effort to maximize conceptual clarity. The entire data set was re-examined to assure that no relevant data were excluded from the thematizations. Co-authors C. T. and B.-M. T. read all interviews, discussed and examined the coding, and validated the themes and overall dimension independently.

Quotations that typify the findings, or when noted in text, indicate that exceptional cases are presented in Table 1. Illustrative quotes are shown by theme, using a numerical code to represent the individual. A bilingual Swedish–English speaker translated the quotes, with translations validated by C. T., also bilingual. Omitted phrases are indicated by... while words within brackets have been added by the authors for clarity.

Findings

Tension between the public and private spheres

The overall dimension *Tension between the public and private spheres* included descriptions of the PCCSP (representing the public sector) encroaching upon what was conceived as the individual woman's private sphere. At the same time, women also tended to make efforts to share some aspects of their own lives (representing the private sphere) with the anonymous public PCCSP organization. This overall dimension is described in relation to the component themes below. These themes are not exclusive but are described separately here for clarity.

Theme 1: Making intimate body parts public—relationships with health-care providers

CCS was described as an examination unlike many others in that it involves an intimate and vulnerable situation, related to a woman's sexuality and reproductive body. These areas of the body were described as extremely private. Women expressed the importance of a secure and trusting relationship with the caregiver who took the Pap smear and thus engaged in intimate contact with her body. Several women described preferring the extra cost of having her own gynaecologist, responsible for all care of her reproductive body including routine examinations like Pap smears. For some women having their own gynaecologist connoted a personal relationship, often maintained over long periods, even generations (W8 & 11).

Some women said they preferred to assume an extra cost² than have an unfamiliar midwife at an ANHC take the Pap smear (W4). For these women continuity in a relationship with a health-care provider was described as more important than the costs or the professional category of the provider. One woman was exceptional, in specifically saying that she preferred a gynaecologist take the Pap

Table 1. Themes illustrated by quotes**Theme 1: Making intimate body parts public—relationship with health-care providers**

W8(Fax): 'My own gynaecologist is good enough for me.'

W11(Int): 'You feel she [gynaecologist] knows you. . . I've known her since I was 17 and . . . she's been with me for the whole journey, and you don't have to explain things and she knows what matters. You feel welcome, and she knows you and . . . that means a lot to me. . . instead of ending up with someone new each time you have to go . . . now my eldest daughter goes there, too.'

W4(Int): 'I don't think you should have to jump around on the examining table just because you get a free examination, it's not that simple.'

W9(Int): 'It feels secure, it feels best. Gynaecologists are specialists . . . they know what they're talking about . . . it's just seemed natural that you should have a private gynaecologist who you trust and know and who you can . . . go to the whole time. Who has your medical journal there. . . There shouldn't be different people who look here and there. . .'

W81(Fax): 'Don't have to come, since I'm not in a relationship yet. BUT SOON!'

W82(Fax): 'It's not necessary for me to have an examination since I unfortunately am not involved in a relationship yet. Luckily, it's slowly but surely improving on that front. FINALLY.'

Theme 2: PCCSP as 'Big Brother'

W7(Int): 'It makes you ill-at-ease, like Big Brother is watching you. I'm not very into the idea that the government should take care of me. People stop thinking for themselves. . . jaha, fifty years old, at that age you have private parts, so typically Swedish, these bad sides of Sweden. Wanting to take care of everything, including my private parts. . .'

W1(Fax): 'I *DID NOT* ask for this examination and I have no desire to do my part to be included in your statistics. . . I am asking you nicely that in the future I can avoid being forcibly called in to your gynaecological check-ups or any other check-ups you may have. With hope that this will be respected. . .'

W17(Fax): 'I think your invitation is 'disgusting' and repulsive. I don't want to be contacted by you again!!! If I ever see another 'invitation' from you, I'll sue you!!!'

W64(Fax): 'It was the most absurd invitation I have ever received. I therefore will not participate in Your examination at any point in the future. . . Now a time has been booked for me, even though this was only an invitation, and (I) have to put time and money in form of postage into saying no to something that I never asked to participate in. Besides, if this is a voluntary examination, then you should not book a time. Instead someone who wants to participate can call and make an appointment themselves if they are interested. And in addition, You want a reason for why one doesn't want to take part in the examination. My explanation to You is: IT IS NONE OF YOUR BUSINESS WHY I DON'T WANT TO PARTICIPATE.'

W34(Fax): 'I have no desire to take part in an examination, organized by someone who sends out a paper with my name and different cancer diagnoses pre-printed and ready to fill in. I take offence at this. . . even if the intention is certainly well-meant. A suggestion: formulate the material differently next time. This paper just spreads worry and fear. I have a private gynaecologist . . . and desire no further correspondence from You.'

W54(Fax): 'I've received quite a lot of these letters. I have written to you several times saying that I do not want to receive any further notices to attend. Now you can just stop terrorizing me. Have my own gynaecologist. If participation is really voluntary, cross me off your damned list.'

W4(Int): 'I don't think it's wrong, absolutely not. I just think that you should be able to choose yourself.'

W48(Fax): ' . . . shouldn't it be my own responsibility to take care of this for my own well being and feeling of health?'

W3(Int): 'I can easily lie, I do that you know, when I go to [names a hospital] and they ask. . . I didn't really tell the truth when they asked me if I'd taken any cell tests, yes, I'd done it I said, because I didn't want to take any there either.'

W2(Fax): 'I'd gladly participate if it were practical. . . But. . . I am not prepared to take time off from work to sit by the phone and try to get through during the short telephone times given, or to go to the health clinic . . . close to home, but . . . not at all near my workplace.'

Theme 3: Dissatisfaction and distrust of screening and the health-care system

W5(Int): ' . . . humiliating to lay on a gynaecologist's examining table at all . . . plus you have to strut around like that and be treated like . . . cattle.'

W41(Fax): 'No confidence in this system since I previously received negative information two-and-a-half months after taking your test. Therefore now have a private doctor who gives me results verbally within 14 days. With best wishes.'

W43(Fax): 'November on 27 I had a test taken at the clinic in [gives name]. After several weeks, I requested the results from you at [names location of the OC]. The answer I received was that my sample had been lost. Someone had registered me, but the sample never arrived at the lab. Since then, I prefer to go to privately instead.'

W45(Fax): 'Don't understand anything! What does technical failure mean? I don't accept this standard reply! With best wishes in reply.'

W12(Fax): 'I don't want to take part in the check-up. . . I don't really think you decrease the mortality from gynaecological cancer with check-ups. . .'

W20(Fax): 'Screening has not been found to entail any health benefits at all.'

W58(Fax): 'There are different opinions about the benefits of this testing—as with mammograms—for others than risk groups. In some cases, these tests can cause detrimental changes instead. The worry, which can also elicit sickness, and which the body is exposed to during the wait for the test results, has also been discussed, from what I have heard and read—I don't belong to any risk group, but am very anxiety ridden. So, please, invite me to a free consultation to help me deal with my anxiety instead, THANKS!!!'

W29(Fax): 'Cervical cancer discovered autumn '79. Despite check-up in Feb. '79'

W3: (Int): 'I am so damned afraid . . . I don't want there to be anything wrong. . . It should work the other way around, and when I think about it logically I should be more concerned about myself. I ought to understand this, but I don't want to go, because I don't want to get a paper like that again.'

W7(Fax): 'Confidentiality isn't respected in [names community with ANHC]. Information in medical records about me and my ailments is a general topic of conversation. It's extremely unpleasant. Thanks, but no thanks. I don't trust anyone anymore. No one's going to entertain themselves at my expense.'

Theme 4: Women's knowledge of themselves versus biomedical knowledge

W11(Int): ' . . . this checking for cell changes and things like that in one's private parts, I think that's important. I believe that regular check-ups and things like that, you feel it more in your body if you don't feel well and. . . I believe that this gynaecological check-up is more important than going and taking some blood test and that sort of thing every now and then. I think you'll feel that more if something isn't okay.'

Table 1. (continued)

W15(Fax):	'I feel healthy. Thanks!'
W7(Int):	'I know my body, my health, and I can open my mouth.'
W32(Fax):	'I think it's [CCS] unnecessary since I don't smoke and I have a sound and healthy lifestyle.'
W36(Fax):	'I find examinations like these unpleasant. I take care of my health instead. For example, am a vegetarian. Vegetarians don't get cancer, rheumatism, diabetes, cardiovascular diseases, AIDS, etc. Read, for example, the magazine [gives Swedish name of health-oriented magazine], and you'll get good information. It's meat, fish and egg-eaters, and milk, cheese, and alcohol and tobacco users who die prematurely. That's already scientific fact. With best wishes.'
W37(Fax):	'I eat large amounts of vitamins and minerals, and have removed the mercury from the fillings in my teeth, which is probably the biggest cause, in every category, of our sicknesses today.'
W58(Fax):	'...I'm not in any risk group...'
W10(Int):	'Yes, there are those kinds of changes you can get when you change partners, there's always that, but it...it hopefully won't happen [laughs]. We've been together for ten years so we can hope it will last [laughs].'

Theme 5: Boundaries in responsibility between the public and private spheres

W6(Int):	'...I know that all cancer medicines are tested on animals and I mean it when I say that, if I ever am afflicted with this disease, I could not accept that sort of help because I don't think it is...morally right...to let so many animals die just because I've gotten myself cancer.'
W7(Int):	'People stop thinking for themselves, there's a shortage of staff in chronic care facilities for the elderly, older people who are put to bed at three pm. The government should take care of those who can't speak for themselves.'
W19(Fax):	'Don't want to take advantage of the county council's bad economy.'
W11(Int):	'When you are so short-staffed, you can use these resources for something else.'
W3(Int):	'No, but at the same time, you should know that I am terribly concerned about it, yes, I have two sisters and I tell them that they should do this [refers to PCCSP] and that it's good.'
W8(Int):	'...otherwise, I think it's fantastic with something like this, yes that you send it to people, or that women can attend. I think it's great because there are many people who otherwise wouldn't go.'

smear instead of a midwife, motivating this with the expertise of the gynaecologist (W9).

The importance of a relationship with caregivers may be indicated by the tendency shown by some women to share aspects of their lives that could be considered private with the anonymous public PCCSP organization. This was explicit in fax messages in which women gave information about their private lives in manners that humanize the anonymous organization of PCCSP. Personal details were sent to the organizational OC fax number, a telephone number without any contact name. For example, private details of relationships were shared, thus also implying an awareness of a link between sexuality and cervical cancer (W81 & 82).

Theme 2: PCCSP as 'Big Brother'

Several moral aspects emerged through the vocabulary women used to describe their sense of being encroached upon by the public sector. The letter inviting women to the PCCSP was described as emanating from an authority that symbolized the public sphere of society and society's control over the individual woman (W7 & 1).

The invitation letter was also said to lead to a feeling of insult (W17, 64 & 34). The letter was described by some using terms like '*absurd*' and '*repulsive*'. It is difficult to know if such descriptions refer to the letter *per se*, or if it is the PCCSP that provoked this strong response. Reminder letters were also found upsetting by some (e.g. W54).

Women described a contradiction between the explicit voluntary nature of PCCSP and a feeling of

an implicit coercion to participate. Motivation for a decision not to attend was requested on the invitation letter itself, as noted previously. Several women were critical of having to respond actively to *not* attend, rather than being proactive in a decision to attend. There were also criticisms of the request for motivation, describing this as offensive when they had not in any way chosen or desired this examination (W4, 1 & 64).

A sense of moral obligation related to societal discourse about individual responsibility to uphold one's health, was also expressed in relation to participation in PCCSP (W48). This could lead to situations in which women said it became problematic to discuss choices with health-care professionals, as exemplified by W3.

Self-determination was also in focus, as women described practical aspects in relation to their lack of influence on the organization of the PCCSP. The PCCSP was described as inflexible and unresponsive to women's needs, e.g. in that they had no choice as to which ANHC to attend for the test and a feeling that children were unwelcome at the PCCSP (W2).

Theme 3: Dissatisfaction and distrust of screening and the health-care system

Previous negative experiences at the PCCSP also influenced women's reasoning. The organization of the PCCSP was described as an '*assembly line*' which treated women like '*cattle*' (e.g. W5). The PCCSP was described as not acknowledging the

individual woman as a subject, resulting in a situation described as 'degrading' or 'disrespectful'.

Some women also described other experiences that influenced their choice to not participate in PCCSP, e.g. waiting 1–3 months for test results. Other women referred to 'technical failures' in the quality of test itself as a source of irritation (W41, 43 & 45).

Non-participation was also motivated by lack of trust in the medical benefits of screening, rather than in the PCCSP itself (W12 & 20). Participation in PSSCP was said to potentially lead to sickness due to anxiety of waiting for results, instead of functioning solely as a means to prevent disease (e.g. W58). Developing cervical cancer despite regular Pap smears or prior experiences with other cancer diagnoses were also reported as reasons for non-participation (e.g. W29 & 3).

Other women described previous negative experiences of health care unrelated to the PCCSP, but which indirectly led to their reluctance to participate in the programme. For example, issues of lack of confidentiality could lead to general distrust of the health-care system and its professionals and an unwillingness to attend PCCSP (W7).

Theme 4: Women's knowledge of themselves versus biomedical knowledge

Another tension between private and public spheres was related to different ways of knowing, as evidenced by differences between women's private knowledge of themselves and their bodies, and biomedical knowledge in the public domain.

There was a lack of consensus among participants as to how well the Pap smear functioned as an indicator of health. For example, gynaecologic examinations were said to be important, as it was difficult to recognize pathologies in the reproductive body oneself. In such cases, women felt that professionals had access to knowledge that the individual woman lacked (e.g. W11). On the other hand, some women felt that they were in tune with their bodies, thereby accessing sufficient knowledge of their health. In such cases PCCSP participation was seen as unnecessary (e.g. W15 & 7).

In addition, some women implied that a healthy lifestyle leads directly to protection from cancer. Religious beliefs could be cited in that disease was controlled by higher beings. Vegetarianism, well-balanced diets with sufficient vitamins and minerals, and ridding the body of dental fillings containing mercury were all methods described by different women as essential for disease prevention (W32, 36 & 37).

As mentioned earlier, some women also indicated an awareness of a relationship between cervical cancer and sexuality. This became apparent as women who described themselves as not living in a risky manner, could also explain that

screening was, therefore, unnecessary for them (W58 & 10).

Theme 5: Boundaries in responsibility between the public and private spheres

Women's reasoning about their choice not to participate in PCCSP raised issues related to boundaries between the public and the private spheres. Women expressing minority points of view described avoiding situations in which they feel pressured to behave in a particular manner. In its most extreme form, a woman who was unwilling to undergo cancer treatment with pharmacological agents developed through testing on animals told of her reluctance to come into contact with health-care professionals at all, although she put effort into maintaining her health in other ways (W6). She avoided all direct contact with the biomedical health-care system for several decades, although she managed to receive birth control prescriptions via telephone. This interview was also exceptional in that she spoke readily of the possibility of developing cancer through her behaviours, assuming responsibility for this possible development.

Other perspectives were more political, with several women in both the interviews and the fax messages reflecting over priorities in publicly financed health care (W7, 19 & 11). Women reasoning in this manner tended to argue that limited public resources should be used for care of the vulnerable and the sick, whereas prevention was a matter for the individual adult. In other situations, women appeared to endorse the societal priorities represented by the PCCSP, but instead reasoned that while others might be benefited, they personally did not need the programme (W3 & 8).

Discussion

This qualitative analysis complements existing literature by exploring the reasoning of a hard-to-reach group, i.e. women who actively chose not to attend a PCCSP. Factors found to be related to women's decisions not to participate in CCS *at all* include a lack of confidence in the benefits of screening, previous negative health care and preventive experiences, a belief in one's own ability to discern health changes or that one was not at risk for cervical cancer, as well as a number of unconventional standpoints on social and political issues. The women in this study who chose not to participate in the organized PCCSP but *did use* private opportunistic screening generally motivated this with direct or indirect criticism of the PCCSP itself. All facets of the PCCSP received some criticism from these participants—from the letter of invitation, through the testing situation itself, to obtaining of screening results. While the benefits of screening *per se* were rarely

questioned among women who took an opportunistic Pap smear, the relationship with the health-care provider in the screening context was described by many as particularly important for their choice. Women's manners of conceptualizing cancer, screening, and health maintenance in general impacted on their reasoning in both types of decision-making. The manner in which women defined and conceptualized distinctions between, and roles and responsibilities of, the private and public spheres appeared central in explanations of decision-making.

In considering these findings, it should be noted that they are based on the views of a selected group of women who took an active role in refusing organized screening. Hirschman's now-classic work from a very different context [29] becomes relevant, as he discusses how people respond to organizations through what he terms 'exit', 'loyalty' or 'voice'. Loyalty in terms of screening implies those who choose to participate in accordance with the programme's norms, whereas exit would refer to the majority of non-participants who choose not to participate in silence. As previously noted, both groups have been studied frequently in the context of CCS, though less often through qualitative approaches. The women in this study represent Hirschman's third category [29], i.e. a minority who actively voice their views as they choose not to participate in the programme. This means that these data are limited in that little information is available about the participants and it should not readily be generalized into clinical application without consideration given to the views of women who do attend the PCCSP. The strength of this study instead lies in affording insight into factors that may be relevant even in other contexts through direct information from this rarely researched group. It is also notable that this study has been carried out in conjunction with a screening programme described as among Europe's best [3,4,30].

This study was facilitated by the use of exceptional caution in recruitment, to avoid possible negative responses from or effects for this group of women. Unstructured interviews were carried out by telephone rather than face to face due to a potential heightened need for anonymity [31,32] when discussing 'negative' choices. The lack of visual cues in telephone interviews may have also eased discussion of controversial responses [24].

The intimate nature of CCS was commented on by many women. While the sensitive nature of the examination [33,34] and the resulting embarrassment and pain which has been the focus of other studies [19,35] were mentioned, these feelings alone were not said to motivate the decision to avoid a Pap smear. On the contrary, it was not the examination alone that was described as sensitive, but rather the PCCSP as a whole. The information

and formulations found in the invitation letter instigated strong emotional reactions in these women; this is in contrast to responses in women who did attend the same PCCSP, who rarely referred to the content of the invitation letter at all [17]. Women's views of the PCCSP as an integrated and comprehensive system suggest a need for increased collaboration around direct and indirect encounters with potential participants, among professionals involved in different stages of the programme.

Tensions between individually oriented health care and the public-health-oriented PCCSP described in relation to difficulties for professionals [36] are apparent in regard to these potential participants in the PCCSP as well. As Bush [37] points out, feminists have often advocated screening as a means for women to gain control over their bodies, but the balance between maintaining control oneself and feeling controlled through bodily surveillance appears particularly delicate among these participants [37,38]. The women in this study call for features to individualize this population-based intervention through a reciprocal relationship with the professional they meet and a personal contact with the impersonal structure of the OC. The importance of self-determination and autonomy in screening and preventive programmes has been highlighted by researchers of different backgrounds [39–41], with ethical conflicts inherent in efforts to promote population health while respecting the individual well acknowledged. Jepson *et al.* [39] expand on classic definitions of autonomy in their screening-specific discussion. The decision-making processes described by women in this study may fulfil Jepson *et al.*'s [39] definition of 'autonomous choice', i.e. acting with 'intentionality, understanding and without controlling influences that determine their actions' (p. 193) in that these women appeared clear about their decisions, their underlying reasoning, and possible consequences. Their choices may also meet Jepson *et al.*'s [39] definition of 'informed decisions' (p. 193) in that women used relevant information about advantages and disadvantages of actions in accordance with their belief systems, although the extent to which these choices were 'evidence-based' is less apparent [39]. Our analysis leads us to suggest that using Jepson *et al.*'s framework to peruse the evidence-base underlying women's 'informed decision-making' about CCS may well be more constructive than discussing potential participants' knowledge versus lack of knowledge.

Tensions between the public and private spheres were also related to the nature of evidence itself, with study data raising issues about what knowledge about women's bodies is relevant, how it can be obtained and who 'owns' such knowledge. How different women viewed these issues appears to differentially impact on their choices (Widmark

et al. [42], accepted pending minor revisions.). This theoretical issue becomes particularly important in light of increasingly rampant discourse regarding the responsibility of the individual for her health maintenance and disease prevention. While we found some women were willing to take unusual personal responsibility and some expense to maintain their health in accordance with biomedical perspectives, others described forms for responsibility which were less acceptable to health-care professionals.

In summary, this study suggests that a minority of women may not be willing to participate in either population-based or opportunistic screening. While these data from a selected group do not provide an adequate basis for suggestions to change the PCCSP on their own, the insights gained from this qualitative study raise important issues to be considered in dealing with the tensions that exist between the needs of the individual and societies in efforts to improve public health.

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Notes

1. Until 1999 (including the time point for data collection), women between ages 25 and 40 received the invitation every third year and every fourth year between ages 41 and 60.
2. The out-of-pocket cost for a private gynaecologist visit including Pap test is ca. 120 Swedish crowns (= ca. 13 Euro).

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