

BMJ Open Perspectives of non-attenders for cervical cancer screening in Norway: a qualitative focus group study

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ABSTRACT

Objective The attendance rate for cervical cancer screening in Norway is currently suboptimal at 69%, and an in-depth understanding of postponement of cervical cancer screening from the perspective of non-attenders is lacking. This study aims to generate knowledge about how non-attenders for cervical cancer screening reflect on booking a screening appointment.

Methods Using the Norwegian cervical cancer screening registry, we identified and recruited women who were non-attenders to screening. Nine focus group interviews were carried out, with 41 women participating in the interviews.

Results Four main themes were generated, which provide a comprehensive understanding of how women who are overdue for screening reflect on their hesitancy to book a screening appointment: 'It's easy to forget about it', 'Women have to arrange their own appointment', 'It has to be a 'must' and 'It's a humiliating situation'.

Conclusion The degree to which women regard screening as important is affected by the nudging strategies employed in the screening programme and the facilitation of attendance provided by healthcare services. Dependence on one's personal initiative to schedule a screening appointment and perception of a lack of responsibility on the part of healthcare services to attend screening may undermine informed and shared decision-making about screening attendance.

INTRODUCTION

Cervical cancer is the fourth most common cancer among women worldwide.¹ Screening for precancerous lesions can radically reduce cancer incidence and mortality; thus, under-screened women are at a higher risk of developing and dying from cervical cancer.^{2 3} According to the national guidelines in Norway, cervical cancer screening attendance rate is currently suboptimal and stands at 69% overall, with this rate being 72% among women aged between 40 and 54 years. The target attendance rate is 80%.⁴

Strengths and limitations of this study

- Focus group interviews (FGIs) are suitable to explore culturally shared attitudes, ideas and experiences.
- Non-attenders were recruited to FGIs via the cervical cancer screening registry, which includes a complete record of all cervical cancer screening visits in Norway.
- Despite efforts to recruit all women who had been invited to participate in the study, women with a relatively high socioeconomic status and non-immigrant background were overrepresented in the study sample.
- Further research is needed to study the prevalence of the shared views described in this study in the non-attending cervical cancer screening population.

The Norwegian cervical screening programme and implementation in healthcare services

The national cervical cancer screening programme (NCCSP) was established in 1995 after decades of widespread opportunistic cytology screening.⁵ All women aged between 25 and 69 years are enrolled in the programme, and the NCCSP issues individual reminder letters to all eligible women who have not had a screening test during the last 3 years. In the reminder letter, women are encouraged to schedule a screening appointment with their regular general practitioner (RGP). Women receive a second reminder if they have not been screened for 4 years; they will continue to be reminded unless they attend as recommended, actively opt out of the programme or reach the exit age. For women aged between 35 and 69 years, the NCCSP is currently transitioning to human papillomavirus (HPV)-based screening with 5-year screening intervals.

The Norwegian healthcare system is universal and publicly funded through taxation. In Norway, all citizens are entitled to an RGP, and each RGP serves about 1100 citizens.⁶ General practice services and specialist

clinics, which operate the public outpatient healthcare services, are mainly financed by fees for service and modest patient copayments. RGPs also serve as gatekeepers to specialist healthcare. In Norway, RGPs usually perform cervical cancer screening; however, some women request a referral to a gynaecologist for reasons that have not been fully explored. In addition, an increasing number of private healthcare clinics that are entirely funded by out-of-pocket payments offer cervical cancer screening in urban areas. RGPs charge about 30€ for a Pap smear, which costs up to 200€ at private clinics. In Norway, women aged 50 years are also by default enrolled in the breast cancer screening programme whereby they receive fixed mammography appointments biennially.

Non-attendance in cervical cancer screening

Studies on non-attendance for cervical cancer screening in Scandinavia have reported that it has a strong correlation with immigration status,^{7,8} unemployment, receiving welfare benefits,^{7,9} low socioeconomic status,^{7,9,10} poor health status,⁸ having a male RGP⁷ and a lack of awareness of cervical cancer screening.¹¹

Forgetting to book an appointment has previously been documented as an important reason for non-attendance.^{12,13} Non-attendance has also been associated with psychosocial and structural issues, such as lack of engagement, embarrassment of having a pelvic examination, procrastination, fear of pain, perception of low cervical cancer risk, experiencing no symptoms, service accessibility and screening costs.^{10,14–19}

Although most women in Norway comply with the general recommendation for attending screening, it is crucial to understand the perspectives of non-attenders. Little knowledge exists about how non-attenders perceive barriers to cervical screening attendance. However, a recent study investigated the perspectives of Pakistani and Somali women in Norway in relation to cervical cancer screening attendance. The study particularly highlights language barrier, lay cultural beliefs, health literacy and reluctance to see the GP and have a pelvic examination.²⁰ There is also limited knowledge about screening attendance as part of a wider sociocultural context, including the perspectives of women with a non-immigrant background.

The term ‘barrier’ might be problematic when studying women’s health behaviour. Its connotation of the existence of a fence, a barricade or a wall that can be bypassed by the right information or removed with the right equipment can be misleading.²¹ To gain a comprehensive understanding of screening non-attendance, we consider it as being embedded in a complex web of discourses and ideas that are both culturally and socially shaped. This implies that we go beyond adding up single factors hindering women’s attendance; instead, we explore how individuals interpret and reflect on their attendance reminders and choice to attend or not attend cervical cancer screening. Public health interventions often use nudging to encourage healthy behaviour. Nudging aims

to influence personal choices subtly without using regulation or coercion so that people are guided to make choices that are in their best interests.²² Thus, the reflections and interpretations of the nudging aspect of the cervical cancer screening programme serve as a point of departure in this study.

Aim of the study

In this study, we aim to explore how non-attenders for cervical cancer screening reflect on booking a screening appointment. The results of this research will help us gain insights into the cultural and social embeddedness of hesitancy to attend cervical screening.

METHODS

Design

Focus group interviews (FGIs) are perceived to be suitable to explore culturally shared attitudes, ideas and experiences²³; they are also useful in addressing issues that may be controversial or taboo.²⁴ Hence, nine FGIs were conducted to discuss and understand issues that women perceive as significant in how they respond to the cervical cancer screening programme. We applied a social constructivist approach and the theoretical perspective of interactionism,²⁵ which turns the attention to inter-subjectivity and the context, as well as how meaning is constructed through interaction (ie, through language, discourse and interpretations of institutional structures).²⁶ We focused on how hesitancy and reluctance to schedule a screening appointment was accounted for and reflected on in the FGIs as well as how the discussions reflected culturally and socially shaped discourses and ideas.

Study recruitment

All women recruited to the study were current non-attenders to cervical cancer screening and had not had a screening test for at least 4 years. We used the NCCSP registry to identify the women who were invited to the study. The NCCSP registry holds complete information on dates and diagnoses of all cervical screening tests performed in Norway. Eligible women who had not been screened for at least 4 years received an invitation to participate in an FGI together with the reminder letter to go for screening. GA and two research assistants phoned about 300 of the invited women aged between 29 and 69 years to personalise the invitation and schedule an interview if they were willing to take part in the study. We carried out four FGIs with women who had not been screened for at least 4 years. Furthermore, we phoned another 400 women aged between 32 and 69 years who had not been screened for at least 7 years and carried out five FGIs with women with this screening status who wished to participate. Each participant received 50€ for taking part in the FGI. We scheduled nine FGIs with a total of 75 women (8–9 per group) of whom 41 attended [table 1](#). Of the 34 women who did not attend, 25 cancelled

Table 1 Characteristics of participants in the FGIs

Attend. status	Education level				Age (years)					Immigration status	
	Secondary	Lower degree (college)	Higher degree (university)	29–39	40–49	50–59	60–69	Born in Norway	Born outside Norway		
FGI 1 (n=6) >4 years	2	2	2	1	1	3	1	6			
FGI 2 (n=5) >4 years	2	2	1	3	1		1	5			
FGI 3 (n=6) >4 years	1	1	5	4		2		6			
FGI 4 (n=2) >7 years	1	1	1		1	1	1	2			
FGI 5 (n=4) >7 years	1	2	1			2	2	2	2		
FGI 6 (n=2) >7 years	1	1	1	1				2			
FGI 7 (n=3) >7 years	2	2	1		1		2	2		1	
FGI 8 (n=7) >7 years	1	3	3	1		3	3	7			
FGI 9 (n=6) >4 years	1	2	3	2	4		2	6			
Total (n=41)	20%	36%	44%	29%	20%	27%	24%	93%		7%	

FGIs, focus group interviews.

Box 1 Statements for discussion in the focus group interviews

- ▶ All women in Norway know enough about the purpose of cervical cancer screening.
- ▶ Women do not take the Pap smear because they are not concerned about their own health.
- ▶ Women postpone the Pap smear because a pelvic examination is very uncomfortable and embarrassing.
- ▶ It matters who performs the Pap smear/pelvic examination and where the appointment is scheduled.
- ▶ Taking the Pap smear seems unimportant because I do not discuss the issue with anyone.
- ▶ I do not like other people to decide on the good choices available for my health.

their appointment at short notice due to illness or other commitments, and 9 did not show up to their scheduled appointment and failed to notify in advance.

Patient and public involvement

Prior to the FGIs, some representatives from the Gynaecological Cancer Society participated in a focus group to give feedback on the study’s aims and design. Based on their experiences as cancer survivors and their work at a non-governmental organisation (NGO), they highlighted issues that they thought were particularly important to be explored in the FGIs.

Materials

The research team developed the interview guide. The guide was informed by the existing research literature on non-attendance and specifically related to the implementation of the screening programme in the Norwegian healthcare services. The interview guide included open-ended questions about cervical cancer and screening, as well as some statements about cervical cancer screening attendance (Box 1). By introducing these statements during the FGIs, we aimed to initiate discussions of and explore viewpoints on various aspects of screening attendance. In the focus group with representatives from the Norwegian Gynaecological Cancer Society, the participants pointed out dilemmas in information campaigns and taboos related to cervical cancer, which improved the relevance of the interview guide and increased the researchers’ sensitivity to the issues addressed in the interviews. We pilot tested the semistructured interview guide in an FGI with female screening eligible students at the University of Oslo.

Procedure

FGIs took place between November 2017 and May 2018. All but one FGI were carried out in meeting rooms at the Norwegian Cancer Society in central Oslo with women recruited from the capital region, while one FGI was carried out at a local healthcare centre in Finnmark with women recruited from a sparsely populated northernmost county in Norway. Following the interview, a short

sociodemographic questionnaire was completed by each participant. The FGIs were undertaken by GA (postdoc, PhD, sociologist) as a moderator. KNS (professor, sociologist) assisted in six of the interviews, and MN (senior researcher, PhD, MD) assisted in one interview. The interviewers were all female. All FGIs lasted about 90 min and were carried out in Norwegian. They were audio recorded and later transcribed verbatim. All participants were deidentified in the transcriptions. The translation of the interview excerpts selected for presentation in this paper was discussed with a bilingual English-Norwegian speaker to ensure accuracy in terms of the literal and figurative content. To protect the privacy of the participants, all data were kept and processed on an IT platform for sensitive data complying with regulations concerning individual privacy. Each participant gave their written informed consent before their FGI.

Analysis

The data were subjected to thematic analyses based on Braun and Clarke's²⁷ principles, which suggest a systematic identification of emerging themes related to the research questions.^{23 27} To enhance the credibility of the analysis, two of the authors cooperated in performing the analysis. GA coded all the data inductively, and KNS coded a sample of the transcripts. The researchers discussed and reached a unified understanding of the number and content of the codes. Using this work, GA identified the lower-order themes, for example, 'the reminder letter as too weak' and 'the reminder letter as optional'. Working together, GA and KNS grouped these themes into higher-order themes, in this case, 'interpretations of the reminder letter'. Finally, four themes were generated, which reflected important patterns related to the research question.²⁷ The four themes were conceptualised using significant statements that were made during the interviews, which we display in the headings below.

RESULTS

'It's easy to forget about it'

The participants regarded themselves as attenders in the screening programme, although they were all overdue for screening. Interestingly, the responses and reflections of the women who had not been screened for at least 4 years compared with those who had not been screened for at least 7 years did not systematically differ.

Initially, the main explanation in the FGIs for postponing screening included typical statements such as 'I just haven't got around to doing it'. Thus, the fact that attendance in the programme strongly depends on women's own initiative to schedule a Pap smear appointment stood out as a critical aspect.

It's easy to forget it 'cause you don't think 'Oh, yes! That I'll do', or 'that I look forward to'. (Quote FGI 5, Participant 4)

However, since screening was simultaneously regarded as important, procrastination was perceived as unwise and without a good reason.

[I] believe that it's wise to do it [attend screening]. It's stupid not to, and there are no good reasons for not attending [screening]. (Quote FGI 7, Participant 1)

Although the participants appreciated the relevance and benefits of attending, the significance of the screening test was challenged in several ways. Family, care obligations and work were very often included in the participants' accounts of why they had postponed screening.

'Women have to arrange their own appointment'

In the FGIs, a typical implicit presentation of one's self included being under-users of healthcare services, and the participants commonly regarded themselves as having a high threshold for seeking professional medical advice. Reasons for seeking professional medical advice were commonly connected to emergencies or cases of 'real' illness. This was, for instance, reflected as an aspiration not to 'overuse' the RGP.

I see the doctor more than enough already for other health issues, so I think, 'Oh no, not another appointment'. (Quote FGI 2, Participant 5)

In this remark, the participant indicates that she experiences screening as necessary to deprioritise because she felt she had already consulted the doctor enough. Thus, by this statement, she implies a need to balance her use of GP services. The opposite view was also expressed. Women who rarely visited their GP felt embarrassed to schedule an appointment for a Pap smear *only*. Thus, since screening was perceived as 'optional' rather than 'critical', a screening appointment only was easily postponed.

Several of the older women said that they had found cervical cancer screening easier to follow-up earlier in their life mainly because they thought that they previously had more acceptable and valid reasons for scheduling a pelvic examination, which concerned reproductive and sexual health.

I took the smear when I had a coil taken in or out or after giving birth or such things. So I don't know if I wasn't already seeing the doctor for other issues I believe the threshold for taking the smear probably would have been higher. (Quote FGI 8, Participant 1)

Several participants said that they no longer followed any pelvic examination routines because they were beyond the fertile age. However, a few younger women also viewed the screening test alone as not being adequately important for scheduling a pelvic examination.

For the major part of the target population, the hesitance of schedule a screening appointment was also linked to the understanding that they felt they carried the responsibility for screening attendance alone.

The service offered is non-existent. Women have to arrange their own appointment, and as long as we leave it up to them, many will not do anything. (Quote FGI 5, Participant 4).

Such opinions were reinforced by the perception that GPs were not always available; for example, some women had to wait for a long time on the phone to make an appointment, which, in turn, made women lose their motivation and initiative.

Several women preferred to see a gynaecologist for the Pap smear. However, uncertainty persisted about ways of accessing a gynaecologist and the terms on which they practised.

I haven't seen a gynaecologist for years, and [I don't know] who should I turn to and do the gynaecologists differ in terms of agreements for reimbursement? And are some cheaper than others? So I've just pushed it away, and I haven't done it [taken the smear], and I don't think I'm gonna do it either. (Quote FGI 8, Participant 7)

The 'best' or 'right' pathway to a gynaecologist was unclear to the participating women. A few had requested a referral to a gynaecologist from their GP, and at least 10 of the women interviewed said that they had scheduled a screening appointment with a private gynaecologist.

'It has to be 'a must''

The participants had all received reminder letters from the NCCSP. They had had a positive experience of receiving reminders and felt reassured that the health authorities cared for them. However, several participants said they had not read the letter or that they had only read the titles or searched for an appointment in the letter.

In several FGIs, the participants pointed out that the open reminder sounded 'too weak', meaning that the reminder did not really nudge them to attend screening. The reminder did not communicate screening as 'a must'.

I don't understand it. If they have money, why can't we just access the right service straightaway [laughter]? Then this [screening] doesn't seem very important, either. If it [cervical cancer] had been really widespread and very dangerous and important to prevent, they would have scheduled an appointment for [us]. Then they'd organise it differently (several other participants: 'Mmmm', affirming.) Then it wouldn't have been voluntary. (Quote FGI 3, Participant 5)

Women commonly regarded the absence of fixed appointments as poor facilitation for attending screening. Moreover, such views allowed interpretations, undermining the rationale and effect of screening. The participants interpret the importance of attending screening in their perceptions of the organisation of screening. *If it is a must, it has to be a must* (Quote FGI 5, Participant 5). Thus, the discussions in the FGIs suggest that the importance

of attendance should be reflected in and consistent with how screening is facilitated and organised.

During the FGIs, cervical cancer screening was frequently compared with breast cancer screening. Breast cancer screening was generally considered more important and serious because women receive fixed appointments to a screening site.

Moderator: Would [a fixed appointment] better help more women [attend]...

4: Yeah, then I believe more people would follow up automatically. Then you don't have to plan for it or book an appointment with the GP. You just have to see the doctor and get over with it.

2: In a way, you get more commanded to go and take the test.

4: You have even less of an excuse not to do it, right? Because it's completely organised and facilitated...

2: But it is still voluntary? You can just cancel it?

4: Yeah, yeah. But it's the mechanism behind it. When somebody has made an effort to organise such a good service for me, then I feel I just can't ignore it! But now I feel it is a bit pointless to get the reminder of taking the smear, of course I know I should! (Quote FGI 5)

This discussion indicates that fixed appointments would make women feel more obliged to attend. In almost all FGIs, the invitation strategy in cervical cancer screening was also compared with invitation strategies for dentists or optician appointments (both private healthcare). They thought that these invitations were much easier to comply with because you receive a fine for non-attendance.

But if it was written 'if you don't show up for this appointment, you'll have to pay 50 €', then I'd attend. But if they just send an [open reminder], I just think 'whatever', and I won't attend it. (Quote FGI 6, Participant 1)

This woman thinks that the current invitation strategy has failed to motivate her to attend screening and that without strong incentives, it is easy to ignore the screening attendance reminders. Thus, she ascribes cervical screening limited importance due to the (too) easily available option of opting out.

'It's a humiliating situation'

As the interviews unfolded, the participants discussed more underlying reasons for postponing screening. All the participants regarded the pelvic examination as uncomfortable and an intimate matter, and most of the women also thought that it was embarrassing and commented that they felt vulnerable. A few also described the pelvic examination as humiliating and the Pap smear as painful.

The participants, in general, held that exposing themselves was worse at a young age due to uncertainty about one's own body and sexuality:

Perhaps you haven't exposed yourself to anybody in that way before, right, and then you're to lie there legs akimbo. (Quote FGI 2, Participant 5)

However, several women expressed the view that exposing themselves did not get any easier with age. In relation to this, women in all FGIs discussed alternative services whereby they would feel more comfortable with having a pelvic examination.

When [I] was young, I used a walk-in-clinic for issues you feel are a bit taboo and a bit icky and a bit scary, and that was a very good service. But, when you turn older, obviously, it doesn't mean that these things get easier [laughter], no, a walk-in-clinic is good for everybody really. (Quote FGI 3, Participant 5)

Concerning their experiences and views of having a pelvic examination, all participants welcomed services that would strengthen privacy and/or reduce practical barriers, such as a dedicated screening site (office/bus), increased availability of walk-in-clinics, having mid-wives perform the test, self-sampling tests and screening being free of charge. Most women explicitly preferred a female practitioner to perform the screening.

DISCUSSION

Public health interventions that encourage screening attendance can be linked to the concept of nudging. Nudging aims to optimise individual choices and behaviour typically with regard to health.^{22 28} Nudging can be understood as a way of implementing policies through individual decision-making and taking individual freedom and responsibility as the point of departure. Yet, it also involves structuring the choice architecture in a way that facilitates the right choice. In screening programmes, setting defaults such as automatic enrolment in the programme (rather than people having to opt in) and open reminder letters or fixed appointments are examples of commonly used nudging strategies.²⁹ This study unpacked several dimensions of non-attenders' hesitancy and reluctance to book a cervical cancer screening appointment, which advances our understanding of how they ascribe meaning to the nudging aspects of the programme. Their perception of personal responsibility and choice results in different interpretations about the importance of screening, which may have significance for their decision on screening attendance. Screening seems to be ascribed considerable importance when it is perceived less as a question of personal initiative or choice. For instance, if a fixed appointment was provided, the responsibility and initiative may, to a great extent, be perceived as shared. This resonates with a study reporting that scheduled appointments increase cervical cancer screening attendance.³⁰ Conversely, when the appointment is understood as solely dependent on individual initiative, and the institutional responsibility for facilitating a screening appointment is perceived as lacking,

screening is ascribed limited importance. This dynamic suggests that when the invitation strategy is not perceived as reinforcing the importance of screening, individuals infer that screening is optional or unimportant.

Nudging in screening is criticised for being paternalistic, undermining free choice and shared decision-making,³¹ and previous studies have suggested that women can be very critical of the perception of screening being compulsory.³² This study illustrates other aspects of the acceptability of nudging strategies in screening, in particular, emphasising the healthcare context for decision-making. The discussions reflected uncertainties about the status or importance of screening within the public healthcare services. This may be exemplified by the perceived uncertainty about whether or not a screening test is important enough to schedule an appointment for, which was distinctly reflected in the FGIs. Such uncertainty has previously been described as a barrier to symptomatic help-seeking^{33 34}; however, to our best knowledge, this has not been described in a screening context. Also, the preference for seeing a gynaecologist and the normalisation of 'going private' for cervical cancer screening question the facilitation and integration of cervical cancer screening attendance in public healthcare. Thus, the discussions in the FGIs illustrate the importance of the implementation of screening in healthcare services to support the choice and initiative to attend screening, which may also facilitate and enhance shared decision-making in screening. This study, in particular, demonstrates that nudging strategies and individual decision-making in cervical cancer screening attendance must be understood within a wider context. Taking into account socially and culturally shaped interpretations of the importance of screening as well as concerns over accessibility and responsibility in the public healthcare service may thus shed new light on cervical cancer screening non-attendance.

Clinical implications

This study suggests that the uptake of cervical cancer screening may be improved by changes in the invitation strategy of the NCCSP and/or structural changes to the screening programme. In particular, the participants' interpretations suggest that the institutional message about the responsibilities of GPs should be framed differently and be better communicated in the reminder letters. Moreover, the views of the participants point to the relevance of considering structural changes to the default invitation strategy, such as use of fixed appointments, HPV self-sampling tests and walk-in clinics. Such changes may facilitate access to screening services as well as enhancing informed and shared decision-making for cervical cancer screening attendance since it may better underscore the importance of screening attendance.

Strengths and limitations

In this study, we used a novel recruitment method to ensure the exclusive inclusion of women who were overdue for screening. While most studies on cervical screening

non-attendance have inferred individual screening status from self-reports or correlates of non-attendance, such as ethnicity,^{15 20 21} nationality¹⁹ or community,^{20 34} we only recruited women who were a priori confirmed as non-attenders in the cervical cancer screening registry, which includes a complete record of all cervical cancer screening visits in Norway.

Since most of the participants had ignored their reminder letters several times, the critical reflections in all FGIs on the dependence of their own initiative are perhaps not surprising. We mostly recruited long-term non-attenders to the study; thus, the views expressed here may not reflect the perspectives of women who have postponed screening for a short period. Note, however, that in the discussions of the groups of non-attenders (>4 years since last screen) and long-term non-attenders (>7 years since last screen), no distinct differences were observed, indicating common experiences across a wide range of non-attenders.

Non-response bias is an inevitable problem in any study that is based on voluntary recruitment. Despite efforts to recruit all women who had been invited to participate in the study, women with high socioeconomic status and a non-immigrant background were overrepresented, which is typical of a study sample where participants have to opt in. Besides, we mainly recruited participants from the capital area. Moreover, the fact that all the participants regarded themselves as 'attenders' for cervical cancer screening is also likely to reflect a participation bias. We did not manage to recruit women who were opposed to screening or women who were not engaged in the screening programme at all, even though many of the invited women were long-term non-attenders.

The discussions in the FGIs included critical reflections on system-level factors and inferences about the importance of screening or lack of it due to the invitation strategy. The participants' relatively advanced education and knowledge in this study probably may have had an important impact on the outcome. Less educated or knowledgeable women may not have articulated their interpretations and views in the same way. Nevertheless, the reflections of our sample provide valuable insights into how non-compliance is both socially and culturally grounded, which is important to be taken into account in efforts of increasing attendance rates in cervical cancer screening.

Contributors BTH, KNS, MN and AT conceived and designed the study. BTH and AT facilitated the recruitment of the participants. GA recruited the participants. GA was responsible for data collection with support and guidance from KNS, MN and JW. GA and KNS coded and thematically analysed the data. GA drafted the manuscript. All authors commented on manuscript drafts and accepted the final version of the manuscript.

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