

General practice-based

ATTENDANCE RATE,

call system for

PARTICIPATION OF WOMEN WITH HIGHER RISK

cervical cancer screening

AND QUALITY ASSURANCE

Ineke Palm
Agnes Kant

GENERAL PRACTICE-BASED CALL SYSTEM FOR CERVICAL CANCER SCREENING

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participation of women with higher risk
and quality assurance**

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op het gebied van de Medische Wetenschappen**

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CHAPTER 1

INTRODUCTION

Motivation and background of the study

In 1942 Papanicolaou and Traut developed a smear test which made it possible to screen for precancerous and early invasive cervical cancer in asymptomatic women.

In the late 1940s Canada was one of the first countries that started a mass screening programme for cervical cancer screening (British Columbia). The United States (1956), England and several Nordic European countries (Sweden, Iceland, Finland) followed.

At that time, there were still reservations toward this new development in The Netherlands. One of the first steps was taken by dr. B Mansens. After visiting Papanicolaou he started a pilot screening project in 1962 in the regions of Arnhem and Nijmegen. During the 1960's, screening projects started in Rotterdam, 't Gooi, and Amsterdam, still without the involvement of the Dutch government. In 1970 the Dutch government for the first time funded a pilot project for cervical cancer screening, which was set up by the Cyt-U-Universitair Foundation in Utrecht¹. After this pilot project (1970-1973) the Health Council of the Dutch government concluded that the Papanicolaou smear test for detecting precancerous lesions of cervical cancer was suitable for implementation on a large scale. In 1975 the government decided to fund cervical cancer screening in three pilot regions, Nijmegen, Rotterdam, and Utrecht. In these pilot projects, women aged 35 to 54 were centrally invited for the screening, and smear-taking took place in mobile screening units. This began in 1976. But soon after this start, under pressure of various factions in the population (in particular the women's movement and patients' movements such as "Voorkomen is beter"), cervical screening projects and activities in the rest of The Netherlands were also funded.

This led to a confused situation, with different screening activities taking place. Next to systematic screening, non-systematic, 'opportunistic' screening by general practitioners (GPs) – as well as gynaecologists and midwives – took place both inside and outside the pilot regions. GPs offered screening activities to women mainly depending on their opinion of the usefulness of this screening. This could differ from no screening, to screening only if women asked for it, to anticipatory care (case finding), to systematic call systems.^{2,3} Anticipatory care was based on the fact that each GP has at least one contact with almost all his patients during surgeries over a period of two to three years. The GP could use this opportunity for prevention in addition to the actual reason for the visit, for example to take a cervical smear. Anticipatory care by GPs raised the percentage of women who had had a cervical smear taken, but also – in the pilot screening regions – it led to futile double screening.⁴

In 1982 the Dutch government decided to discontinue the centrally organized screening program as set up in the pilot regions, despite the positive results.^{5,6} It was decided to integrate cervix screening in general practice. The main reason for this decision was the overlap between the different screening activities. This decision was followed by years of discussion of the preferred screening approach. During this discussion even the benefits of cervical screening in general were again challenged. But in 1985 principle agreement of cervical cancer screening was reached, with the discussions focusing on financing and other practical aspects. Finally, in 1989 a national screening programme for cervical cancer was started in The Netherlands for women aged 35 to 54, with an screening-interval of three years. Women were identified for screening by the population register (census data). Contrary to the pilot pro-

grammes, no central organisation and coordination was implemented; in this programme the GP had to take the smears, while Local Health Authorities and local municipal governments were responsible for inviting the target group. As a consequence, in most regions women received a letter signed by the director of the Local Health Authority or alderman of the local community inviting them to make an appointment with their GP for cervical screening.

There was profound concern that with this set-up participation (compliance) with screening might become a major problem. Cervical screening is only effective if a substantial part of the target population is screened. In the national programme the initiative is left to the women to contact her GP. Monitoring compliance and sending reminders is a major problem, as different actors are involved and there is no coordination between those inviting and taking the smear.

In addition to the concern about the level of participation, a shortcoming of the set-up of the national programme was the difficulty of excluding women without a need for screening from being invited – for example, where a smear had recently been taken, or with a history of total hysterectomy. In order to exclude these women, Local Health Authorities would need information from the GPs and/or the pathology laboratories. Inviting these women might lead to spurious screening and a waste of scarce facilities. In addition, it might be painful and confusing.

Another anticipated shortcoming was the follow-up of women with preinvasive cytological abnormalities. The cytopathology laboratories were assigned the responsibility to advise on the follow-up actions, but implementation of follow-up was left to the GP. Again, no supervision was foreseen for the interface between laboratory and GP. Both the level of participation of women in need of a screening smear and the level of follow-up of abnormal screening results influence the effectiveness of the programme.

The concerns of the effectiveness of the screening programme were reasons for the Dutch College of General Practitioners (Nederlands Huisartsen Genootschap) to initiate an intervention project that provided the basis of the study of this thesis. In this study, GPs invite women for cervical cancer screening: the Nijmegen general practice-based call system for cervical cancer screening.

Objective and Aims of the study

The objective was to evaluate a general practice-based call system, in comparison with the national programme.

The aims were to determine:

- (i) the participation (compliance) of the target population;
- (ii) the efficiency of the follow-up of abnormal smears;
- (iii) the cytological quality of the cervical smears; and
- (iv) the feasibility of implementing the system in general practice.

The study was funded by the Ministry of Welfare, Health and Cultural affairs, and the EC programme 'Europe against Cancer'.

Outline of the thesis

In 1989, in a pilot study, a general practice-based call system was introduced in three general practices.

In Chapter 2 this pilot study is reported on. After promising results the intervention, the general practice-based call system, was introduced in another seven practices.

Chapter 3 presents the participation rates of the general practice-based call system in ten general practices compared to the national call system. The results are based on the invitations during the first year of the study 1990.

Chapter 4 presents the participation during the total study period (1990-1992).

Chapter 5 examines the feasibility of introducing a general practice call system on a large scale; it reports on a postal survey to assess the general practitioner's attitudes towards the current screening programme and to examine the opinion of general practitioners on a general practice based-call system.

The positive results of the intervention and the high percentage of GPs who were willing to participate in a call system led to the introduction of a general practice-based call system on a larger scale. Chapter 6 reports on the implementation of a regional general practice-based call system.

There are indications that in mass screening campaigns for cervical cancer a substantial number of the non-attenders are women at a particularly high risk for cervical cancer. A personal invitation for screening by the woman's own GP might achieve a higher attendance of women with an elevated risk for cervical cancer, compared to the national screening programme. The next two chapters test this hypothesis.

The feasibility of comparing risk profiles by a questionnaire on risk factors for cervical cancer was first tested in a pilot study as described Chapter 7. This was the basis of a study in which risk profiles were compared for the two inviting systems. This study is presented in Chapter 8. The final part of the thesis are two studies on the quality assurance of the cervical cancer screening.

The expectation was that involvement of the GP in a general practice-based call system for cervical cancer would increase their responsibility for an adequate follow-up of abnormal smears. This is reported on in Chapter 9.

Finally, an evaluation of the quality of the samples of cervical smears taken by general practitioners, and also by some practice assistants, in the Nijmegen region are presented in Chapter 10.

The thesis concludes with a discussion (Chapter 11) and summary. The methods of the Nijmegen general practice-based call system for cervical cancer screening are presented in the appendix and form the methodological product of the study, available for other regions in the country.

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CHAPTER 2

MASS SCREENING FOR CERVICAL CANCER. THE EFFECTIVENESS OF DIFFERENT CALL SYSTEMS. A PILOT-STUDY

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Introduction

From experiences with screening programmes in the Nordic countries, as well as from the results of screening in three pilot regions in the period 1976-1985 in The Netherlands¹, a positive effect of screening on the reduction of the incidence of and mortality from cervical cancer was established.² In 1985 the Dutch government decided to introduce a national screening programme. This programme began in 1989 in several regions. In contrast to the pilot regions, where from a regional centre the invitations to participate in screening and control of compliance took place, a noncentralized setup was used for the national screening programme. The general practitioners (GPs) take the smears while the Local Health Authorities manage the call system. Consequently in most regions women in the target population (aged 35-54) receive a letter from the Local Health Authority inviting them to make an appointment with their GP who then takes the smear. An important question is whether this decentralized screening programme setup can achieve the same positive results can be achieved as the former pilot programmes. Cervical screening is only effective if a substantial part of the target population is screened. In the national programme the initiative is left to the women to contact their GPs. Compliance of women can thereby become a major problem.

Before the national screening programme, cervical cancer screening in general practices was mainly nonorganised and opportunistic, taking place mostly during visits related to oral contraceptive use or at a woman's request. Therefore, primarily young women were screened. A few practices had experiences with systematic case-finding.³⁻⁶ Recently in this journal results were presented of a systematically organized in three general practices.⁷

At the Nijmegen Institute of General Practitioners an intervention study begun in september 1989 to compare the national call system with a GP-based call system. In this study, where 10 general practices participate, the women are invited to a screening by their GPs. The GPs get insight into which women attend and which do not attend, making it possible to send a reminder to nonattenders. Moreover, this call system allows GPs to exclude women for whom it is not medically necessary from being invited for screening. Therefore women are not unnecessarily confused, irritated or upset, and unnecessarily smears are prevented.

Most GPs were involved in the intervention study from January 1990. In three practices the study already began in September 1989. The 514 women registered with these three practices who were in the target group for cervical screening were a 'pilot' for the intervention project. This paper describes the methods and results of this pilot study.

Methods

Three general practices were involved in the pilot study. The women registered with these practices were invited for screening by their own GP. For each practice a control group was selected from women living in the region who were invited for screening by the national call system.

Practice A is a health centre with four GPs, situated in a large district of Nijmegen with relatively new houses. The majority of the women registered with this centre lived in this district (99%). In 1989, women were invited for screening by their GP in a standard letter with a predetermined appointment on a specific date. In case of absence the appointment could be rescheduled. A reminder was not sent.

The control group for Practice A consisted of women of the target population living in another district of Nijmegen also with relative new houses and with comparable socio-economic status as the district where Practice A is situated.

Practice B is comprised of two GPs in a rural village. Almost all residents of the village were registered with this practice (90%). The village is situated near the city of Nijmegen but forms a separate community.

The control group for Practice B consisted of women living in a village with a comparable urbanisation rate, also situated near the city of Nijmegen.

Practice C is a practice with three GPs in a typical commuter village. About 10% to 20% of the residents were registered with this practice. They live scattered throughout this village.

The control group of Practice C consisted of the women living in the same village who were not registered with this practice, and therefore were invited by the national call system.

In 1989, the women of Practices B and C were invited by practice assistants. The women received a standard letter with the request to make an appointment for a cervical smear. If a women did not respond to this letter, she received a reminder by phone. The smears were taken by practice assistants.

Results

The target population (aged 35-54) for screening in practices A, B, and C consisted of 238, 111 and 165 women, respectively. The medical registrations of the practices were checked to determine which women had to be excluded from invitation because of medical reasons. Since this was not possible in the control groups, in these groups all women were invited. To enable comparison between the intervention practices and the control groups, the attendance rates for all groups were calculated for all identified women. Therefore, in this comparison the women excluded for medical reason in the practices were regarded as nonattenders.

In all practices the attendance rates were considerably higher then in the control groups (Table 1). The age distribution of the intervention practices differed from the control groups. A stratified analysis showed that this did not lead to bias of the results.

Table 1 Attendance rates

Practice	Control groups		General practices		
	N	attendance (95% CI)	N	attendance without reminder (95% BI)	with reminder (95% CI)
A	979	38% (35;41)	238	56% (50;63)	*
B	149	40% (32;48)	111	59% (50;68)	65% (56;74)
C	1.361	49% (46;52)	165	60% (53;67)	73% (66;80)

* no reminders

For the intervention practices a protection rate – the percentage of women who in any way were protected for cervical cancer – was also calculated (Table 2). Protection was defined as women who attend for screening and women who were not invited for screening because of a medical reason (total hysterectomy or women who had had a recent – within one year before invitation – smear taken). In the three practices a total of 82 women (16%) were not invited for screening due to medical reasons.

Table 2 Protection rate

Practice	Protection rate
A	71% (65;77) ¹
B	86% (80;92) ²
C	88% (83;93) ²

¹ no reminder² including reminder

Discussion

The results of the pilot study are promising, indicating a higher attendance for screening if GPs invited the women. The attendance rates in the control groups are low. In the region of Nijmegen this attendance is 35% (33%-35%). In other regions the attendance also seems low. This makes the present set up of the national screening programme questionable. Former screening programmes in the pilot regions showed that women are prepared to participate in screening; other experiences with GP-based call systems show a high compliance.⁷

Conclusions can not yet be drawn from the results of this pilot study. The intervention project in which 10 practices participate has to gain more insight into the possible positive effect of a systematic GP-based call system. Also, it is yet to be shown whether the same effect will subsequently occur in different general practices with different practice managements. It is also unclear is also how the attendance rates of the national call system will develop.

Implementating a call system within a general the practice requires necessary adaptations and time investments of the organisation. As part of the invitation process, practice registrations must be checked to determine which women are to be excluded from invitation for medical reasons.

In the pilot study a reminder seems to increase the compliance to screening. If this effect is continued in the intervention project, the introduction of reminders must be considered. For the practices this will mean extra effort, including monitoring compliance. In the intervention project, the total time investments of the general practices will be inventoried. After all, a positive effect of a GP-based call system has to be weighed against the efforts to be made.

In addition to screening attendance, the quality of the cervical smears is also an important issue. A high percentage of inadequate smears means extra burden for the GPs and unnecessary concern for the women. The percentage of inadequate smears because of lack of the endocervical cells (EC-) are quite different between GPs: in 1985 this was estimated as 10% to 50% of the smears. The sampling devices used seem to be important for the quality of the cervical smear.⁸⁻¹⁰

A study in which cervical smears were taken by practice assistants showed that the quality of the smears were almost comparable to those taken by GPs.¹¹ In several practices of the intervention project also smears are taken by practice assistants. The percentage of inadequate smears will be evaluated, in relation to the sampling device used as well as to the smear-taker.

The monitoring of follow-up after abnormal pap smears is an important prerequisite for the success of a screening programme. In the former pilot screening programmes the GP already was responsible for follow-up. During this programme the outcome of further diagnostics appeared to be unknown for a large number of abnormal pap smears.^{12,13} Especially in cases of moderate dysplasia there often was no follow-up. A number of the intervention project participating practices have set up monitoring systems for follow-up, with varying extents of follow-up activity. The effects of these monitoring systems will be evaluated.

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CHAPTER 3

PRELIMINARY RESULTS OF A GENERAL PRACTICE BASED CALL SYSTEM FOR CERVICAL CANCER SCREENING IN THE NETHERLANDS

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Summary

A study was undertaken in Nijmegen, in the Netherlands, to compare the attendance rate following a call system for cervical cancer screening organized by general practitioners, with the attendance rate resulting from the Dutch national call system. Women are invited for screening on a three yearly basis and in 1990 1616 women were identified by nine practices as being in the appropriate age group (35 to 54 years) to attend for cervical screening while 10387 women were identified by the national call system. The attendance rate among the 1101 women in the rural general practices was 58%, compared with 49% of 4154 women in the matched group receiving an invitation from the national call system. The attendance rate among 515 women in the urban general practices was 55%, compared with 41% of 6233 women in the matched group receiving an invitation from the national call system. Invitations from general practitioners resulted in similar percentages of women in all age groups attending for screening. Four general practices sent a reminder letter or made a telephone call to non-attenders. A reminder increased the attendance rate from 58% to 70%.

It is concluded that a general practice based call system for cervical screening produces a higher attendance rate than the national call system.

Introduction

Screening programmes in the Nordic countries have reduced the incidence of cancer of the cervix and the mortality rate.^{1,2,3,4,5} However, the studies identified the necessity for an organized programme for cervical cancer screening to ensure high attendance rates and adequate follow-up of cytological abnormalities.^{1,2,3,4,5}

In the United Kingdom, most screening programmes have not been organized systematically and have had a limited effect.^{6,7,8} The main problem with the British programmes is the inadequate means with which to contact women, particularly those in older age groups who have a higher risk of developing cervical cancer.^{9,10,11} Call and recall systems which have been set up in several districts and general practices improved the attendance rate for cervical screening.^{12,13,14,15,16} In May 1988, a national cervical cytology call and recall system was introduced in the UK. This system is based on the computerized age-sex register. However, the accuracy of these databases is problematic and needs to be improved.^{17,18}

In the Netherlands, screening for cervical cancer was initiated by the government in three pilot regions in 1976. The pilot programme which was systematically and centrally organized and was carried out in special mobile units. It reached a high proportion of the target group (attendance rate 65-75%) and showed a decline in incidence of invasive squamous cell carcinoma.^{19,20}

However, during the pilot study many general practitioners and gynaecologists took smears outside the systematic screening organized from the special mobile units. Many women were screened in both contexts, with only marginal improvement in coverage. The combination of organized and opportunistic screening led to a limited additional health effect, but the large number of smears resulted in high costs.²¹ To reduce double screening, the Dutch government

allocated the task of taking smears to general practitioners.

A nation-wide screening programme for cervical cancer was started in the Netherlands in 1989. Every three years, all women in the age group 35-54 years were invited for a cervical smear. Contrary to the pilot programme, this nationwide programme is not organized centrally. The women received a letter from the Local Health Authority inviting them to make an appointment with their general practitioner who then took the smear. Because those inviting the women were different from those taking the smears, it was difficult to monitor compliance and send reminders. The attendance rates resulting from the nationwide screening programme were disappointing. Local Health Authority districts who evaluated responses to screening have found overall attendance rates of about 40% (unpublished data). It was thought that involving general practitioners in calling women for screening would reduce unnecessary double screening. If general practitioners were involved in the call system and acquainted with the schedule, it was thought they would try to screen women according to the schedule. Prior to invitation, general practitioners are able to exclude those women who were screened recently. It was also thought that the personal bond between the women and their doctor would promote participation in screening.

A project was therefore undertaken in 1990 to set up a call system for cervical screening within general practice. This study analyses the attendance rate resulting from a call system organized by general practitioners and compares the outcome with the results of the national call system.

Method

Selection of practices

General practices in the region of Nijmegen which had a computerized age-sex register and which sent cervical smears to regional health laboratory were eligible for the study. These practices were asked to participate and nine were willing (some other practices had heard about the project and wanted to participate but were excluded as this self-selection would have resulted in bias).

None of the practices selected had taken any initiatives to organize cervical screening or had shown any special interest in cervical screening.

Selection of the women

In the first year of the study (1990) all invitations for screening in the participating practices were organized by the researchers. The population register (a register of names, addresses and dates of birth held by the local registry office) was used as the main source of information to identify women due for screening, that is women aged between 35 and 54 years. In January 1990 the researchers received a data file from each of the nine participating general practices of the names of the women whose dates of birth indicated that they should be invited in 1990 according to the three yearly national call schedule). The researchers checked this list against the list from the population register to identify those women who were registered with a non-participating practice. Lists of these women were sent to the local health authority, who

invited them to make an appointment with their general practitioner for a cervical smear. The researchers could therefore ensure that all women due for screening are invited.

From the data file from each of the general practices a monthly list of potential invitees was compiled, which distributed the women equally over 12 months. In order to ascertain eligibility, every month, each general practice received a checklist for each woman asking whether she had recently had a cervical smear (within one year); whether she had undergone a total hysterectomy; and whether she was receiving follow up for previous cytological abnormalities. The list was then returned to the researchers and they sent each eligible woman a letter on behalf of the general practitioner, inviting her to make an appointment with her general practitioner for cervical screening.

Four of the general practices also sent reminders or made a telephone call to non-responders after four weeks.

Urban and rural practices

Screening in the region of Nijmegen during the pilot project (1976-1985) had shown a lower attendance rate in urban areas compared with rural areas,¹⁹. Three out of the nine participating practices were situated in an urban area. Most of the women registered with one of these practices lived in the same district of the city as the practice and as each other. According to data from the local government department of social economic research there was little difference in socioeconomic factors between this district and the whole city. Therefore for these three urban general practices, controls were defined as all women from the same city who were invited by the national call system. The other six general practices were in rural areas. For these practices, a control group of women was defined as all women comparable rural communities who had been invited by the national call system.

Analysis

After one year, the attendance rate as a result of the general practice call system was compared with the attendance rate resulting from the national call system. All women identified through the population register on the basis of their age were invited in the control group, whereas only those women who were eligible were invited from the nine practices. To enable comparison of the two groups, the attendance rates (and 95% confidence intervals²²) for both groups were calculated for all women who were identified through the population register on the basis of their age.

Because of a possible effect of age on the response rate, a difference in age distribution might bias the results. Therefore age-specific attendance rates for both groups were compared. These series were tested on equality using the chi square test; the expected numbers of attenders and non-attenders in the group identified for screening by their general practitioner were estimated on the basis of the observed age-specific attendance rates among the women invited by the national call system.²³ Homogeneity of the effects within the age groups was tested using the chi square test in which the ratios of observed to expected attenders and non-attenders were the weighting factors.²³

Results

A total of 1616 women were identified in the general practices for cervical screening: 515 women from urban practices and 1101 from rural practices. Of these women, 284 (17.6%) did not need to be screened: 158 women had had a recent, 13 were receiving follow-up for previous cytological abnormalities, and 113 had had a total hysterectomy. As a consequence, 1332 women were invited by the general practices for a cervical smear.

In the control group, 10 387 women were invited by the national call system: 6233 from an urban area and 4154 from a rural area.

The overall attendance rate among women identified by their general practitioner was 56.9%, compared with 44.4% of women invited by the national screening study. Excluding the 284 women found to be ineligible for screening, the attendance rate among women invited by their general practitioners was 69.0%. Among the women identified by general practices in the rural areas, 282 attended for screening, an attendance rate of 54.8% (95% confidence interval (CI) 50.5% to 59.1%). In the urban control group, 2552 women attended 40.9% (95% CI 39.6 to 42.1%). In rural practices, 637 women attended, a rate of 57.9% (95% CI 55.0% to 60.8%), compared with 2056 women in the rural control group (49.5%, 95% CI 48.0% to 51.0%).

When analyzed by age group, the attendance rate among women identified by the general practices was higher than among those invited by the national screening programme for each age group (Table 1). This was true for both the urban and the rural areas. In the urban practices the test for equality of attendance rates showed a difference in attendance rates ($X^2 = 35.1$, 6 degrees of freedom $P < 0.001$). The non-significant result of the test on homogeneity showed that the effect was the same in each age group. Therefore, age cannot account for the differences in attendance rates between the two groups of women. In the rural intervention group the test for equality of attendance also showed a difference in attendance rates ($X^2 = 44.7$, 6 df, $P < 0.001$). The test on homogeneity ($X^2 = 12.24$, $0.05 < p < 0.1$) showed borderline homogeneity of the effect for the separate age groups. Examination of the contribution of each age group revealed that the year of birth 1940 contributed 5.53 to the chi square score of 12.24. This age group therefore showed a stronger effect, which is also shown in Table 1. In the rural area, the attendance rate among women born in 1940 who were invited by their general practitioner was 17.6% higher than among those invited by the national call system; overall the difference in the rural area was 8.4%

In four study practices (three in rural areas and one in an urban area) non-attenders received a reminder. After the first invitation, the overall attendance rate among the 574 women identified in these practices was 58.2% (95% CI 54.2% to 62.2%). The reminder increased the attendance rate to 70.2% (95% CI 66.5% to 73.9%). Of the 574 women in these four practices, 92 (16.0%) were not eligible for screening. Excluding these 92 women, the attendance rate was 83.6%.

Table 1 Attendance rates for cervical screening among women identified by their general practitioner and by the national screening programme, by location and by age

Year of birth	% of women attending in			
	Rural areas Invitation from GP*	Invitation from national programme	Urban areas Invitation from GP*	Invitation from national progr.
1937	57.4 (n=122)	43.6 (n=388)	47.2 (n=36)	31.8 (n=648)
1940	60.1 (n=143)	42.5 (n=485)	52.2 (n=23)	37.2 (n=744)
1943	51.1 (n=135)	47.6 (n=502)	52.9 (n=34)	39.1 (n=704)
1946	63.7 (n=215)	51.9 (n=657)	52.6 (n=97)	43.1 (n=1026)
1949	56.5 (n=184)	51.7 (n=719)	57.5 (n=87)	45.3 (n=951)
1952	54.6 (n=163)	49.6 (n=718)	57.7 (n=111)	41.7 (n=1051)
1955	59.0 (n=139)	54.5 (n=685)	55.1 (n=127)	43.6 (n=1109)

n = total number of women in group.

* Attendance following reminders not included.

Discussion

The study found the call system organized on a general practice basis resulted in a 13% higher attendance rate for cervical screening than the national call system. Excluding, the ineligible women not invited by the general practitioners, the attendance rate would have been even higher.

Studies in several countries have shown that a well organized screening programme can achieve a 70% attendance rate which results in substantial reduction in both incidence of and mortality rate from cervical cancer.^{1,2} Among the four practices who sent a reminder letter or made a telephone call to non-attenders, the attendance rate increased from 58% to 70%. Excluding the 92 women found to be ineligible for screening, the rate in these practices was 84%, thus only 16% of the women were true non-responders.

The lower attendance rate among women in urban areas compared with women in rural areas found in previous study¹⁹ was also found in the present study. Invitations from general

practitioners resulted in similar percentages of women in all age groups attending for screening. Because older women (who are also those most at risk of cervical cancer) usually are least likely to participate in screening programmes,^{10,11} this is an important advantage of the general practice based call system.

Involving general practitioners in the organization of a cervical screening programme will not only lead to a higher attendance rate, but also to a more efficient organization of cervical screening in the general practice. For example, in four of the general practices in this study, most of the smears were taken by the practice assistant (a member of the staff with specific medical and administrative training), often during specially organized screening times. In addition, all of the general practices in this study have set up a system to monitor the follow up of women with positive cytological smears. In the near future it is our intention to study the effect of the intervention on unnecessary double screening.

In order to set up a general practice based call system, it is necessary to select women according to age and general practitioner. At present in the Netherlands, there is no central registration system in which women can be selected according to the general practice with which they are registered with. A practice's computerized age-sex register could therefore be used. A postal survey showed since the start of the project a considerable percentage of the general practices had become computerized.²⁴

This study shows a clear effect of personal invitations signed by woman's general practitioner. In addition to this effect there is the effect of the reminder. The question arises as to who is responsible for sending reminders to non-attenders. In this study the general practitioner who invited the women and also organized the smear to be taken also organized the reminder system as the general practitioner was aware of who had been invited and could thereby monitor responses. But, if different partners are involved in inviting women for screening and taking of the smears, as in the Dutch national call system, organizing of such a reminder system becomes more complicated, and a few regional health authorities in the Netherlands have such a system. If call systems are set up within general practice, it seems more practical for the general practitioners to set up reminder systems.

The results from the first year of the study show that a general practice based call system for cervical cancer screening produces a higher attendance rate than the national call system. That women in older age groups were likely to attend is an important finding. It seems therefore that there are major advantages in a general practice based call system; the final three-year results of this study should offer more insight into this.

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CHAPTER 4

A CALL SYSTEM FOR CERVICAL CANCER SCREENING IN THE NETHERLANDS ORGANISED ON THE BASIS OF GENERAL PRACTICE

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Summary

Objective – Does a general practice-based call system for cervical cancer screening achieve a higher attendance of women eligible for screening, compared to the Dutch national call system?

Methods – Cohort study in general practice/public health region in the eastern part of The Netherlands. Women registered in ten general practices received an invitation for cervical cancer screening from their general practitioner. A control group was invited by the Local Health Authority (national call system). The controls were group-matched on urbanisation.

Subjects – 5,173 women were invited by their general practitioner (intervention group) and 32,099 were invited by the Local Health Authority (control group).

Results – The overall attendance rate in the intervention group was 55% (rural areas 56%, urban areas 54%) compared to 43% in the control group (rural areas 48%, urban areas 39%).

For all age groups and during each year of the study, the attendance rate in the intervention group was higher.

A reminder by the general practitioner to women not responding to the initial invitation increased the attendance rate an additional 9%.

Conclusions – The general practice-based call system for cervical screening resulted in a higher attendance rate than the national call system. Therefore a general practice based call system is preferable to an invitation from the Local Health Authority and should be considered in the organisation of screening for cervical cancer. The model is a promising option for implementation in routine practice in The Netherlands and elsewhere.

Introduction

Cervical cancer screening programmes have been shown to be effective in several countries¹⁻⁵. However, these studies also identified the necessity for an organized programme of cervical cancer screening to ensure high coverage of the target population and adequate follow-up of cytological abnormalities. The current question is not whether cervical screening should or should not be performed but how a programme can be most effectively to greatest effect.

A nationwide screening programme for cervical cancer was started in the Netherlands in 1989. As in the UK, the general practitioner (GP) is involved in cervical cancer screening. The programme is set up in the following way:

- every three years, all women aged 35-54 years are invited for a cervical smear;
- the municipal population registers are used to determine the women to be invited;
- the women receive an invitation by letter from the Local Health Authority to make an appointment with their GP;
- the GP takes the smear.

The chosen setup of the programme had a number of shortcomings. The first concerns the attendance rate. Because different authorities invite the women and take the smears, major problems arise in monitoring compliance and sending reminders. Also the attendance rates of the 40 to 50% for this nationwide screening programme are disappointing.

Another shortcoming of the setup is the difficulty in excluding women who have had a total hysterectomy or recent smear from being invited for screening. In order to exclude these women, Local Health Authorities would need information from the GPs and/or the cytological laboratories.

These shortcomings were the reasons for an intervention project in which the GP would be involved in the invitation part of the screening programme. In The Netherlands general practices have a defined patient population which enables the selection of patients by sex and age from the practice list. In the absence of a central national register that provides information on patients listed with practices, such a system can only be setup within individual practices.

In this intervention project, ten general practices established a structured call system and monitoring system for cervical cancer screening within the practice. The aim of the study was to determine whether a general practice-based call system can achieve a higher compliance with this screening programme compared to the national screening programme. Preliminary results of this study showed a 10% to 15% higher attendance rate for the screening without reminder and 20% to 25% higher attendance with reminder compared to the national call system⁶. In this paper, the results of the total study period 1990-1992 are presented.

Methods

Selection of the practices

General practices in the region of Nijmegen with a computerized register allowing sorting by age and sex and which sent the smears to the regional screening laboratory were eligible for the introduction of a general practice-based call system. The computerized age-sex register was necessary to select the women aged 35 to 54. At the start of the project only eleven practices fulfilled these criteria. Ten were willing to participate in the project.

Selection of women for screening

The municipal population registers were the source to identify the women due for screening, that is, women aged 35 to 54 years. The ten GPs with the call system sent lists of women they were going to invite for screening (intervention group) to the researchers. The researchers matched the practice lists with the list drawn from the population registers. Women who were listed at participating practices were removed from the list of the population register; the remaining women received an invitation from the Local Health Authority (control group).

Urban and rural practices

The screening in the region of Nijmegen during the pilot project (1976-1985) showed a lower response rate in urban communities compared to rural areas,⁸ therefore the controls were group-matched on urbanization. Three of the participating practices in the intervention group were situated in an urban community. For these general practices, a control group was defined as all women from the same city who were invited by the national call system. The other seven general practices in the intervention group were situated in rural areas. For these practices, a control group was selected from comparable rural communities invited by the national call system.

The general practice-based call system

The women of the ten participating practices were invited for cervical cancer screening by a personal letter from their own general practitioner. Women were excluded from being invited by their GP in cases of (a) a recent cervical smear (within one year); (b) total hysterectomy; (c) being under follow-up for previous cytological abnormalities; (d) personal circumstances, contraindicating an invitation for screening.

Six of the general practices also sent reminders to invited women who failed to contact the practice. After four weeks the non-responders received a second letter. At the start of the project some practices reminded women by phone. Because of the increased workload, however, they soon switched to a letter reminder.

Analysis

Data on total numbers of invited women were gathered from the practice lists (intervention group) and the population register (control group). Data on attendance were gathered from the laboratories where the GPs send their cervical smears.

The registers of the cytological laboratory recorded the reason why smears were taken (for preventive or medical reasons). This way, it was possible to gather data on preventive smears taken from both the intervention and control groups. A woman was defined as an attender if a preventive smear was registered in the year of invitation or in the first three months of the following year.

The attendance rate from the general practice-based call system was compared to the attendance rate from the national call system in the control group. In the intervention group only the eligible women were invited, but in the control group it was not possible to exclude women from being invited for medical reasons.

To enable a comparison between the intervention group and the control group, the attendance rates in both groups were calculated for all identified women. So *in this comparison* the women excluded for medical reasons in the intervention group were regarded as non-attenders.

Owing to a possible effect of age on the attendance, age-specific attendance rates for the intervention and control groups are compared. Also, the homogeneity of the results was examined over the different age groups by stratification on age.

Table 1 Identification of women non-eligible for a cervical smear test in the intervention group

Year invitation	Number of women	Recent smear taken or in follow-up		Total hysterectomy		Total non-eligible	
		N	%	N	%	N	%
1990	1490	161	11%	100	7%	261	18%
1991	1870	214	11%	138	7%	352	18%
1992	1813	193	11%	121	7%	314	18%
Total	5173	568	11%	359	7%	927	18%

Table 2 Attendance rates and 95 per cent confidence intervals (CI) from general practices (exclusive reminder) and control groups

	General practices				Control groups			
	N	Attendance No.	Attendance %	95%CI	N	Attendance No.	Attendance %	95%CI
Urban								
1990	516	282	55%	[51;59]	6232	2552	41%	[40;42]
1991	530	297	56%	[52;60]	6068	2355	39%	[38;40]
1992	506	260	51%	[47;55]	6243	2376	38%	[37;39]
1990-1992	1552	839	54%	[52;56]	18543	7283	39%	[38;40]
Rural								
1990	974	566	58%	[55;61]	4154	2056	49%	[47;51]
1991	1340	751	56%	[53;59]	4854	2284	47%	[45;49]
1992	1307	706	54%	[51;57]	4548	2184	48%	[46;50]
1990-1992	3621	2023	56%	[54;58]	13556	6524	48%	[47;49]
Total	5173	2862	55%	[54;56]	32099	13807	43%	[42;44]

Table 3 *Age-specific attendance rates for the general practices and control group*

Age	Practices			Control group		
	N	attendance		N	attendance	
Urban		No.	%		No.	%
53	88	40	45%	2095	688	33%
50	113	46	41%	2097	787	38%
47	126	64	51%	2311	839	36%
44	237	111	47%	2909	1158	40%
41	274	157	57%	2868	1214	42%
38	316	184	58%	3059	1298	42%
35	398	237	60%	3204	1299	41%
total	1552	839	54%	18543	7283	39%
Rural						
53	379	192	51%	1367	556	41%
50	482	251	52%	1595	687	43%
47	492	251	51%	1701	754	44%
44	646	373	58%	2303	1138	49%
41	549	315	57%	1932	966	50%
38	572	340	59%	2248	1152	51%
35	501	301	60%	2410	1271	53%
total	3621	2023	56%	13556	6524	48%

Table 4 *Attendance rates and 95 per cent confidence intervals (CI) from six general practices before and after a reminder*

	N	Attendance first invitation			Attendance after reminder		
		No.	%	95%CI	No.	%	95%CI
1990	574	334	58%	[54;62]	402	70%	[66;74]
1991	1243	684	55%	[52;58]	780	63%	[60;66]
1992	1065	580	54%	[51;57]	661	62%	[59;65]
1990-1992	2882	1598	55%	[53;56]	1843	64%	[62;66]

Results

Invitation

In the intervention group 5,173 women were identified for screening in the period 1990-1992; 3,621 came from the rural practices and 1,552 from the urban practices. Of these women, 18% were not invited for medical reasons: 11% because of a recent smear or follow-up for previous cytological abnormalities and 7% because of total hysterectomy. These percentages were the same for each year of the project (Table 1). As a consequence, 4,246 women from the intervention group were invited.

In the control group, 32,099 women were identified and invited by the national call system: 18,543 from an urban area and 13,556 from a rural area.

Attendance rate

The overall attendance in the intervention group was 55% compared to 43% in the control group. In the rural region the attendance was 56% compared to 48%, and in the urban region, 54% compared to 39%, respectively. In each year of the study this difference was significant, for both the rural and the urban region (Table 2.).

When analyzed according to age, the attendance rate in the intervention group was higher than in the control group for each age. This was true for both the urban and the rural areas (Table 3.).

In six of the intervention practices, the non-responders received a reminder. After the initial invitation, the attendance rate in these practices was 55%. The reminder increased the attendance to 64%, bringing, as a results, the overall attendance rates for these practices was 21% higher than the control group (Table 4.).

Discussion

The aim of this study was to assess the effects of a practice- based call system on the attendance of women in a screening programme for cervical cancer. The attendance was higher for the general practice-based call system than the national call system and, after a reminder, the response rate increased further. The six general practices which also sent reminders had a 21% higher attendance than the national call system.

The attendance in the control group corresponds with the disappointing attendance in the national screening programme in The Netherlands.

Since the criterium for participating in the general practice- based call system was computerization, selection could have resulted in bias. The 'early computerized' practices might have had more screening activities: therefore their patients might be more likely to participate because they are accustomed to these activities. However, a regional conducted survey showed no relation between 'computerization' and 'screening activities within the practice' and 'attitude to screening programmes/activities'⁷. Also management style of 'early computer-

ized' practices might cause a certain type of patient to choose these practices, thereby affecting the compliance to screening. In the urban areas this might be the case. In the rural areas however, patients usually choose the closest practice, since the distances between practices are greater.

The possible selection based upon management style and attitude towards screening is more likely to show biased compliance to the reminder rather than the first invitation, because compliance to the reminder primarily reflect a more personal approach.

The first twenty years of cervical screening in the UK have had a limited effect.^{9,10} The main problem with the programmes was the low coverage.^{11,12,13} In an effort to improve organisation of cervical cancer screening in the UK, all health authorities were instructed to introduce a cervical cytology call and recall system in 1988. Since the change in payment to general practitioners for cervical screening in the UK, screening activities increased significantly. The 1990 general practitioner contract sets targets on which payment for cervical screening depends. Payments are triggered on reaching 50% to 80% of the target population. Coverage of the target population between 1989/90 and 1992/93 increased from 61% to 83%.¹⁴

Well-organized screening programmes in Scandinavia showed that a 70% attendance rate can be achieved.^{1,2} The results of the intervention group of our study approach this figure.

An important question is whether women with a higher risk for cervical cancer participate in screening. Results from pilot screening programmes showed that more cervical abnormalities were found in smears taken from women who attended after a reminder.¹⁵ This implies that, with a reminder, more women in the high-risk group are being reached. Possibly, these women need an extra push to attend a screening; the personal letter from their GP or a reminder may provide such an incentive.

In addition to a higher compliance with the screening – and thereby greater effectiveness of the screening programme – the general practice-based call system has another important advantage. The GP can exclude women from being invited for medical reasons. This not only reduces the number of unnecessary smears but also needless 'emotional pain' and irritation for the women who have had a hysterectomy. This study showed that exclusion for medical reasons involves a substantial number of women; in the participating practices, 18% did not need a screening test.

Since there is no central registration by which women can be selected according to the GP with whom they are registered, a general practice-based call system can only be set up within individual practices. We conclude that a general practice-based call system is preferable to an invitation from the Local Health Authority. But it is another question whether this system can be introduced on a larger scale.

A condition for inclusion in the study was computerization of the general practices. At the start of this study only about 10% of practices were computerized. But during the study period, this increased to 48% in 1993 and 80% in 1994, in accord with automation rates in The Netherlands.

A survey conducted of all GPs in the region showed that the large majority of them (91%) were willing to participate in some way in a general practice-based call system⁷. Currently, the call system has been introduced on a large scale in the region.

The incidence of cervical cancer is relatively low, but it is a serious health problem. Well-organized screening programmes can reduce the incidence of cancer of the cervix and the mortality rate by 50 to 60%.^{1,3,4,5}

The main problems in national screening programmes for cervical cancer are identifying women at risk, compliance, and the number of opportunistic and unnecessary smears.^{13,16,17} The general practice based call system in this study demonstrated the possibility of increasing the participation and at the same time excluding women for whom a smear was not relevant. This may contribute to a more effective and efficient allocation of screening resources. In our view, this study demonstrates the value of an approach to screening for cervical cancer that combines the best of public health and individual health care. The model appears feasible on a larger scale in The Netherlands, and in all other countries where data from a practice list are available.

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CHAPTER 5

IMPLEMENTATION OF THE NATIONAL CERVICAL CANCER SCREENING IN GENERAL PRACTICE AND FEASIBILITY OF A GENERAL PRACTICE-BASED CALL SYSTEM: THE GP'S OPINION

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Summary

Thus far, the response to the nationwide screening programme for cervical cancer in the Netherlands, which was started in 1989, has been disappointing. One way to improve response is to involve general practitioners in the call system.

A postal survey was conducted to review the implementation of the current screening programme in general practice and to examine the willingness of general practitioners to participate in a general practice-based call system. The response rate to the survey was 90%. The general practitioners were dissatisfied with follow-up, cost and time spent and compliance of women.

Of all respondents 60% had already set up a call system within the practice or were willing to do so; another 31% were willing to participate in a regionally organized practice based-call system.

On the basis of the results of this study a centralized general practice-based call system is recommended. The next step is to study the applicability of this system in a pilot programme.

Introduction

After promising results obtained from screening in three pilot regions,^{1,2} a nationwide screening programme for cervical cancer was started in The Netherlands in 1989.

Every three years, all women aged between 35 and 54 receive an invitation by letter from the Regional Health Authority, to make an appointment with their general practitioner. Women are identified through the Registry Office. The general practitioners take the cervical smears while the laboratory makes the cytological diagnosis. In case of a positive smear the laboratory makes recommendations to the general practitioner for follow-up.

Thus far, the response rates to this nationwide screening programme have been disappointing, ranging from 10 to 70%.

As in this nationwide screening programme the Regional Health Authority invites the women and the general practitioner takes the smears, it is a major problem to monitor the response and to send reminders. A second problem is that the inviting authority, the Regional Health Authority, is not able to exclude women from screening for medical reasons such as total hysterectomy, recent smear or follow-up for previous cytological abnormalities. This leads to unnecessary and occasionally embarrassing invitations. Another problem is the responsibility for the follow-up of women with preinvasive cervical abnormalities. Who takes care of the follow-up: the laboratory, the general practitioner or the woman concerned?

As a consequence, the need to review the organization of the Dutch screening programme for cervical cancer has become evident.

One of the options, in which the general practitioner will be responsible for invitation and follow-up, is currently the subject of study. The study concentrates on a general practice-based call system in the Regional Health Authority district of Nijmegen.³ In this study ten general practices invite the women, monitor compliance and are able to send reminders, take the smears and take care of follow-up. Prior to invitation, those women are excluded who

have been screened before or who have undergone hysterectomy. Preliminary results of this study show a high response rate and an efficient organization of cervical screening in the general practices.³ The results are comparable with studies in the UK based on general practice register or on the Family Practitioner Committee register.^{4,5,6,7} In the Netherlands there is no central registration system to identify the women according to the general practices with which they are registered. The register of population is the main source of information. Therefore the implementation of a general practice-based call system requires additional cooperation of general practitioners to match the (computerized) age/sex register of the practices with the register of population.

A postal survey was conducted to review the implementation of the current screening programme in general practice. The aims of this study were to assess the general practitioner's attitude towards the current screening programme and to examine the opinion of general practitioners on a general practice-based call system.

Method

A postal survey of local general practitioners was conducted in the Regional Health Authority district of Nijmegen.

For this survey a questionnaire was drawn up which was tested by several general practitioners. As a result, some alterations were made to increase its acceptability and comprehensibility.

In the questionnaire questions are asked about:

- acquaintance with the current national call system;
- organization of the current screening within the practice;
- follow-up;
- attitude towards prevention within general practice;
- attitude towards the current screening programme;
- willingness to participate in a general practice-based call system;
- computerization.

A list of the Regional Health Authority was used to identify all general practitioners of the district. Excluded were (i) general practitioners who already participated in the study of the general practice-based call system³ and (ii) general practitioners who had retired from practice.

The questionnaire was sent to the remaining general practitioners with an introductory letter and a stamped addressed envelope. After two weeks a postal reminder was sent to the non-responders. The general practitioners who had still not responded received a second reminder by telephone after another two weeks.

Results

The questionnaire was sent to 136 general practitioners. The response rate was 90% (Table 1).

Implementation of the screening programme in general practice

— Communication with the inviting authority

The majority of general practitioners was acquainted with the age range and screening interval of the target population, but not with the details: only a few general practitioners were aware of the actual birth year cohorts invited during a year and none of them were acquainted with the monthly local call schedule (Table 2).

Table 1 *Response rate of general practitioners to postal survey (n=136).*

	Number	%
Direct response	81	59
After first reminder	20	15
After second reminder	22	16
Total response	123	90

Table 2 *Are the general practitioners acquainted with the call system?*

	Number	%
Not acquainted with target population and local call schedule	16	13
Acquainted with target population (recommended age range and screening interval)	97	79
Acquainted with target population and the yearly local call schedule (which years of birth per year)	10	8
Acquainted with target population and the monthly local call schedule (which year of birth per month)	—	—
Total	123	100

— Who takes the cervical smears?

Most of the general practitioners took the cervical smears themselves. Only 2 general practitioners (2%) delegated the taking of the smears to the practice assistant, whereas 28% of the general practitioners expected to involve the practice assistant in the future.

— When are the smears taken?

Almost all general practitioners took the smears during the regular surgery hours. Less than 5% of the general practitioners had separate sessions for cervical smears.

— Monitoring of follow-up

Of all general practitioners 50% monitored the follow-up: they sent an invitation for follow-up or contacted women who did not respond to recommended repeat smears.

Almost 40% monitored all women with cervical abnormalities and upwards of 10% only monitored the women with a recommendation for a repeat smear within 6 months or less.

Approximately 50% of the general practitioners had no monitoring system, one out of five of these general practitioners intended to set up a monitoring system in the future.

— Communication with the laboratory

Only 21 general practitioners (17%) were informed periodically by the laboratory if women did not respond to recommended repeat smears.

Satisfaction with the current national screening programme

Screening for cervical cancer was accepted by almost all general practitioners (Table 3). The majority supported the view that screening reduced the incidence of and mortality by cervical cancer. Most of them agreed that the screening test should be performed by the general practitioner.

Table 3 Acceptance of screening by general practitioners

	Number	%
View on effect of cervical screening on reduction in incidence or mortality		
– large effect	104	85
– moderate effect	16	13
– slight effect	2	2
total	122	100
Satisfaction with taking smears by general practitioners		
– satisfied	114	96
– dissatisfied	5	4
total	119	100

The general practitioners were dissatisfied with several aspects of the screening programme. The following major problems were mentioned:

- monitoring of follow-up (82%);
- payment to general practitioners (78%);
- compliance of women with screening (73%);
- time spent by general practitioners (72%);
- management of Pap2 (and concern about “trivial” repeat smears (67%);
- the registration and evaluation (68%).

Participation in a General Practice-based Call System

Of all respondents 74 (60%) had already set up a call system within the practice or were willing to do so, although one out of two general practitioners wanted extra support to carry it out (table 4). The following conditions were mentioned: computerization; payment; administrative and organizational support. Of the remaining 49 general practitioners 38 (31%) were willing to participate in a regional call system based on information from the practices. Finally, 11 general practitioners (9%) rejected both the regional general practice-based and the general practice-based call system.

Table 4 *Willingness to participate in a call system*

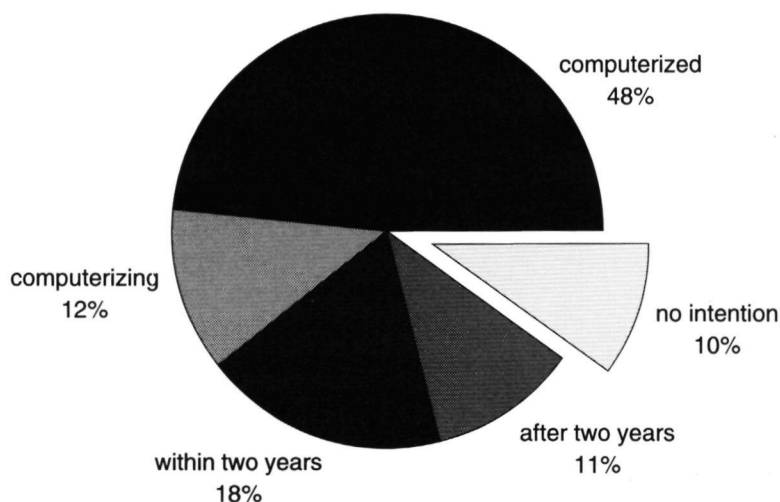
	Number	%
willing to set up a call system within the practice		
– already operating a call system	10	
– willing to set up a call system	18	
– willing to, provided that...*	46	
Total	74	60
willing to participate in a regional call system based on information from the practice:		
– in order to improve response (by reminders and/or call attention during surgery hours) and to check on reasons for non-invitation	14	
– only in order to improve response	23	
– only in order to check on reasons for non-invitation	1	
Total	38	31
No interest in either of call systems	11	9
Total	123	100

* The following conditions were mentioned: computerization (17%); payment (59%); administrative and/or organizational support (20%); unknown (2%).

Computerization

In the Regional Health Authority district of Nijmegen about 75% of the general practitioners used a computerized registration system or expected to computerize within two years (figure 1). Another 11% expected to computerize later.

Figure 1. Computerization of GPs



Discussion

In general, the general practitioner's satisfaction with the current national screening programme is moderate. The main problem mentioned by general practitioners, is the follow-up of cervical abnormalities. Although most of the general practitioners agree that the screening test should be performed by the general practitioner, they are dissatisfied with cost and time spent. Possible improvements such as separate sessions for taking smears and delegation of taking the smears to the practice assistant are found in only few general practices. This will save time, the more so since it separates the preventive smears from the cure system.

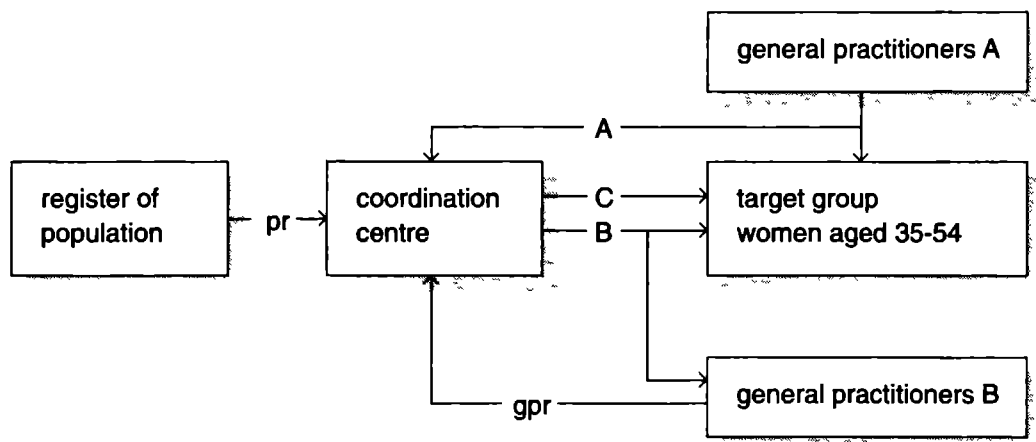
Another problem connected with cost and time, is the recommendation of a repeat smear in case of Pap2, because of the high frequency (25%) of the smears with this diagnosis. Currently the effect of a repeat after Pap 2 diagnosis is investigated further.

A majority of the general practitioners were dissatisfied with compliance. The communication between inviting authority and general practitioners is insufficient. Most of the general practitioners are unaware who are invited, so they do not know which women do not participate. For this reason the general practitioners are not able to improve response and to check on reasons for non-compliance.

This study demonstrates that the majority of general practitioners in this region are willing to participate in a call system, but many are in need of extra support.

Therefore, to introduce a general practice-based call system, a support system is necessary.

Figure 2. A regional general practice-based call system



One option to perform a centralised general practice-based call system is the system of figure 2. In this system the register of population is used as the main source of information to identify women due for screening (pr). A regional centre coordinates inviting and is responsible for (i) arranging a regional call schedule (equal distribution over the calendar year of the birth year cohorts invited during a year) and (ii) taking care that all women due for screening are invited.

General practitioners can participate in this system in two ways:

- A. The general practitioner sets up a call system within the practice. The age/sex register of the practice is used to identify the women due for screening. Excluded from invitation are women who have been screened before or who have undergone hysterectomy. The remaining women receive an invitation from the general practitioner. Every month a list of the women due for screening is sent to the regional centre, where these lists are matched with the register of population.
In the questionnaire 60% of the general practitioners indicated to opt for this organizational set-up.
- B. The general practitioner cooperates by identifying the women due for screening through the age/sex register of the practice and sending these data to the regional centre (gpr). The centre matches the data with the data of the register of population and sends the invitations, which are formulated as if coming from the general practitioner. Every month a list of the women invited is sent to the relevant general practitioners.
In the questionnaire 30% of the general practitioners indicated to opt for this organizational set-up.

All women registered with a non-participating practice received an invitation by the centre (C). Problems with women who are perhaps not invited because of inadequacy of age/sex registers of the participating practices, are resolved by matching the age/sex registers with the accurate register of population.

From the centre the general practitioners can be supported by:

- an education programme for practice assistants with practical training in taking smears;
- instruction to general practitioner about software which supports the participation in the call system and the introduction of a follow-up monitoring system;
- optimizing data communication;
- quality assurance by monitoring the effectiveness of the system in terms of compliance, proportion of unsatisfactory smears and follow-up compliance.

This study has shown that many general practitioners have a positive attitude towards a general practice-based call system. On the basis of the results of this study we recommend a regionally organized general practice-based call system. The next step will be to study the applicability of the suggested call system in a pilot programme.

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CHAPTER 6

EFFECTIVENESS AND FEASIBILITY OF A GENERAL PRACTICE BASED CALL SYSTEM FOR CERVICAL CANCER SCREENING. A REGIONAL IMPLEMENTATION PROJECT

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Abstract

After positive results of a general practice-based call system for cervical cancer screening in the region of the Local Health Authority of Nijmegen, the effectiveness and feasibility of the GP-based call system was tested on a larger scale.

All GPs in the region were invited to participate. Extensive information and support was provided to try to maximize participation of GPs. At the same time, data were gathered on computerization and applicability of GP information systems. The reasons for non-participation of GPs were inventoried. After one year, the feasibility on the GP-based call system within the practices was evaluated with a mail questionnaire.

The GP-based call system, inclusive reminder, led to a attendance rate of 58% and a protection rate of 84%. A vast majority of the GPs are willing to participate in a GP-based call system. The most important reason for non-participation was non-computerization. Only a few problems arose at the introduction of the GP-based call system within the practices. The GP information systems appeared to be useful for application for the cervical screening.

Introduction

Cervical cancer is to an extent a limited, but serious, health problem. Mass screening can reduce the incidence of and mortality from cervical cancer significantly. But screening can only be effective if well-organized, with high compliance of the target population and adequate follow-up of preinvasive lesions.¹⁻³

In the mass screening programme for cervical cancer screening in The Netherlands, which started in 1989, the compliance with screening was low. Compliance of women with screening, although differing per region, was mostly not higher than 40%. At such low compliance levels it is expected that women with the highest risk hardly participate. Furthermore, a substantial number of preventive smears are taken outside the screening programme.⁴ The crux of the problem is that the organization of the screening programme is limited to the invitation of women for screening by the community/Local Health Authority. The smear-taking is delegated to the general practitioners, but they are unaware which women are invited. Sending reminders thereby is hardly possible. Also, women are not selected before invitation. All women are invited, including women who recently had had a smear taken or who have had a total hysterectomy. This can cause unnecessary confusion and irritation.

A possibility for improving the organization of the screening is to delegate the responsibility for inviting and smear-taking to the same instance. An intervention project in Nijmegen, in which this responsibility was delegated to GPs, showed positive effects.⁵⁻⁷

A postal questionnaire showed that in the region of Nijmegen 90% of the GPs were willing to participate in a regionally organized general practice-based call system.⁸

If the general practice-based call system would also be effective and feasible on a regional scale, the call system could gradually be transferred to other regions.

This paper describes the experiences with the implementation of the general practice-based call system in the Local Health Authority region of Nijmegen in the period 1994-1995, according to the following key questions:

1. How can a feasible and adequate organization of a regional GP-based call system be set up?
2. How effective is a regional GP-based call system?

Methods

The Local Health Authority region of Nijmegen includes 11 communities and 99 general practices. The condition for participation was computerization of the general practice. Since this was unknown, all practices were invited to participate while simultaneously an inventory of computerization of the GPs in the region was made.

A lot of attention was paid to the promotion of the project, in order to achieve a higher participation.

After a detailed invitation for participation by mail, two reminders followed by mail non-responders were also reminded by phone. For GPs who were interested, information meetings were organized. After these meetings GPs were invited by letter to enrol in the project.

During the preparation phase a coordination centre was already set up, from which the above-mentioned was organized. This centre was also responsible for carrying out the project and coordinating inviting the women, supporting the participating general practices, and the quality assurance. In addition, the centre encouraged participating practices to introduce reminder and monitoring systems for follow-up within the practices. Finally, courses were planned for smear-taking by practice assistants and for using the GP-information systems to invite patients for screening.

After one year, the feasibility of the GP-based call system within the practices was evaluated with a mail questionnaire.

The effectiveness of the GP-based call system is evaluated in terms of attendance and protection rate.

The attendance rate of the invited women was calculated for 1994. In order to establish the attendance it was not possible to use the complete records of the regional pathological laboratory as was done in the intervention study.^{6,7} Data on attendance were therefore derived from the registration in the general practices. The earlier former intervention study showed that this registration corresponds well with the records of the laboratory.⁷ The attendance was determined only for general practices which participated in the project during the whole year (1994).

Results

1. Implementation of the regional GP-based call system

— *Participation of general practices*

29 practices were not able to participate because of non-computerization.

Of the 70 computerized practices, 56 (80%) were willing to participate. Fourteen practices were not interested. Nine were not willing to participate because of the time investment and/or the lack of extra financing. Of five practices the reason for nonparticipation was unknown.

— *computerization of general practices*

The following GP-information systems were in use: Promedico, Microhis, Elias, Arcos and Amice. Additionally, one GP had developed his own system. For each GP-information system in consultation with the software supplier and the users society, the possibilities were studied for the necessary data selection and exchange. This appeared not directly possible for all information system. Some of the Microhis users still had to switch to a update. For Elias, the update had to be adapted in consultation with the supplier.

Therefore, the eight practices with these systems were not able to participate directly in the implementation project.

A second problem was that some practices had not yet finished computerization or still had to solve other organizational problems. For these reasons 11 practices were not able to participate directly.

Ultimately, it was possible for only 37 of the 56 interested practices to participate.

In these practices there was obvious need for instructions in the use of the GP information system for selection of patients for screening. Therefore plenary courses were organized for the Promedico-users. For the other GP information systems, users manuals were sufficient.

— *Coordination of the invitations*

Women were invited by year of birth, according to the national call schedule. Regional schedules were set up for the participating practices and involved communities. The intention of the schedule was to offer smears equally to the laboratories.

Since not all practices were computerized or willing to participate, a part of the target population still had to be invited by the regular call system, the community/Local Health Authority. The two call systems were matched in order to ensure that all women were invited and did not receive duplicate invitations.

— *Matching call systems*

Since the two call systems were carried out in parallel, a special software for the matching was developed in the preparation phase. With this software the data files of the population registers and practice registers could be matched automatically. The bases for invitation were the population registers of the communities, because the intervention project showed that these registers were up-to-date.

Clear arrangements with the communities and practices were made for the delivery of the data files of the women who had to be invited.

The delivery of the data in general was adequate, although on average a quarter of the practices needed a reminder by phone. At the coordination centre the call systems were matched and the women who were listed as patients at participating GPs were removed from the invitation file of the communities. The files were returned to the concerned communities who invited the remaining women of the target group.

The software developed for this matching process could easily be adapted to the different GP information systems.

The matching took place per community and per GP information system, and lasted on average 10 minutes.

Automatic matching occurred if the date of birth and the first four characters of the proper name corresponded. This matching process was analyzed for the community of Nijmegen. Automatic matching took place for 83% of the women. For 8% the data – zip code and/or address – of the women in the file differed from the data in the population register and had to be decided per matching which data concerned the same women. Nine percent of the women were not matched because they were not registered in the population register. This concerned women who lived in another community, women who had moved, or women whose address was unknown at the population register.

Table 1. Problems with the GP-based call system for cervical cancer screening in 35 general practices

Task	problem		definition problems
	no	yes	
printing files	32	3	– inexperience with this application of the GP information system
printing labels	26	9	– inexperience with this application of the GP information system
file on floppy	25	10	– inexperience with this application of the GP information system
checking patient list for eligibility	29	6	– incomplete data – defining non-eligible women: (non-total hysterectomy, religious, Pap2)
inviting	26	9	– cooperation with communities – inaccurate zip code

— *Feasibility in the general practice*

The questionnaire was sent to 35 practices with a 100% return rate. Two practices were not yet involved in the project, or had been involved for only short time and did therefore not receive a questionnaire.

In general, the GPs were positive on the feasibility of the general practice-based call system: 8 indicated 'very much feasible', 20 'very feasible', 6 'reasonably feasible' (1 unknown). None of the GPs indicated 'moderately feasible' or 'poorly feasible'.

The implementation of the invitation led to few problems.

The problems mainly concerned the lack of experience of working with the GP information system for this purpose (Table 1).

Table 2 shows a summary of the tasks carried out by practice assistants. These were mainly administrative and automation tasks.

However, in more than half of the practices the smear-taking was also delegated to the practice assistants (15 practices), or was intended to be delegated to them (5 practices). In 16 of these 20 practices the practice assistants participated in the course on smear-taking (Table 3). Often, separate surgery hours were scheduled by the practice assistants (9 practices).

The number of preventive smears per invited group varied from 8 to 35 per practice, with extremes of 40 and 50. The mean was 20 smears, which resulted in a time investment of about 180 minutes (Table 4), 21 minutes for each invited group (7 groups). The time investment for the invitation was on average 100 minutes for each group, or 12 hours per year.

Table 2 *Involvement of practice assistants in the GP-based call system*

Task	GP	assistant	both	other*
printing files	8	24	3	—
printing labels	7	21	1	6
data on floppy	9	23	2	1
checking patient list for eligibility	5	22	8	—
inviting	—	35	—	—
taking smears	20**	—	15***	—
registration attendance	3	24	7	1
sending reminders	1	29	—	5

* other: by administrator or coordination centre, or none if this task is not carried out

** of these 20 practices, 7 practice assistants participated in the course on smear-taking, and in 5 practice assistants intend to take smears in the future.

*** of these 15 practices, 9 practice assistants participated in the course on smear-taking.

Table 3 *Involvement of practice assistants in smear-taking in the practices of which the assistants participated in the course*

practices	smears taken by practice assistants?				total
	yes	in future	unknown	no	
in implementation project	9	5	–	2	16
not in implementation project	5	1	1	1	8
total	14	6	1	3	24

2. Effectiveness of the GP-based call system

Thirty-one of the 36 practices sent reminders to non-attenders.

During all of 1994, 24 practices participated and registered attendance with screening. The attendance rate in these practices was 58%, including a reminder which increased the attendance rate by 10%. This attendance rate was lower than in the intervention study (64%). In both studies the reminder increased the attendance by 10% (Table 5).

The 'protection rate' was 74% without and 84% with a reminder.

The attendance rates (with reminder) in the general practices varied from 39,5% to 77,9%. The 'protection rates' in the practices varied from 61,7% to 97,6%.

Table 4 *Average time investment in cervical cancer screening in 35 general practices per invited group*

Task	average	range
Smear-taking	180 minutes	100-280 minutes
Inviting		
– printing files	18 minutes	5- 60 minutes
– printing labels	12 minutes	5- 60 minutes
– data on floppy	10 minutes	1- 30 minutes
– checking patient list for eligibility	30 minutes	5-160 minutes
– invitations	30 minutes	8-120 minutes
– total time inviting	100 minutes	30-265 minutes
Reminders	20 minutes	5-180 minutes

Table 5 *Attendance rates in 1994 of general practices participating in the implementation project compared to the intervention project*

	attendance		protection rate*	
	excl. reminder	incl.	excl. reminder	incl.
intervention-project				
– intervention-group	54%	64%	72%	82%
– control-group	39%			
implementation-project	48%	58%	74%	84%
* attendance + non-eligible				
Non-eligible				
	recent smear taken		total hysterectomy	
intervention-project	11%		7%	
implementation-project	18%		8%	

Discussion

Because of the shortcomings of the national screening program, the Health Insurance Council has established a number of conditions for an improved organization of the national screening programme. In the new set-up each region now has to make a regional plan for the organization of cervical cancer screening in association with all instances involved. These plans have to meet a number of conditions concerning the interval of screening, the target group, and follow-up. In addition, the plan has to fulfil a number of practical conditions, including quality assurance, computerization, process-control, evaluation, financial liaisons and responsibility.⁴

A GP-based call system can fit very well in such a regional plan for cervical cancer screening. It also works well in the foreseeable greater role of the GP in screening activities.

The revised Dutch College of General Practitioners Guideline for cervical cancer screening supports the introduction of a general practice-based call system.⁹

This implementation study showed that the general practice-based call system is feasible on a larger scale, if a number of limitations are solved. The main barrier appeared to be the lack of computerization in some practices. The computerization rate, however, is rapidly increasing. It might be considered to predetermine a part of the extra financing for preventive actions in the general practices for computerization.

Of the computerized practices, a vast majority (80%) appeared to be willing to participate in such a call system. However, for a limited number of practices the time investment and/or

financing were barriers. This is a barrier which needs serious attention, since the number of tasks of GPs is increasing. Perhaps a solution can be found by extra financing for expanding the activities of the practice assistant.

Finally, there appeared to be problems related to practice organization or information systems, leading to non-participation of practices. In the end this was the cause for non-participation for one-third of the practices.

The introduction of the call system within the practice was considered to be feasible, in part due to the support from the coordination centre. Although, mainly for the use of the GP-information system in order to select women for cervical cancer screening, there were many additional requirements for support.

A substantial part of the extra activities were carried out by practice assistants. It is therefore important to involve practice assistants in the project from the beginning of the implementation.

The delegation of smear-taking to the practice assistants was experienced as positive and an enrichment of their job.¹⁰

The variability of the GP-information systems used was a solvable problem. Eventually, all of these, sometimes with small adjustments, appeared to be appropriate for invitation for screening applications. Uniformity in information systems could be an aim, especially within a region.

The patient registers of the GP proved to be adequate for invitation. An important advantage of the matching of the data is that the coverage of the target group is as optimal as possible. On the one hand, women are reached who are not registered at a population register. On the other hand, possible incorrectness of the GP-register can be completed or corrected with use of the population register. Importantly, because matching is performed at the coordination centre, no confidential data of the practices are passed on to the communities.

In the previous intervention project in Nijmegen, a personal invitation from the GP showed a increase in the attendance rate of 15% without a reminder and 25% with a reminder. Furthermore, 18% of the women were excluded from invitation because they were not eligible: 11% because of a recent smear (within one year) and 7% because of a total hysterectomy. In the intervention group the protection rate was high: 91% of the target population had had a smear within the last three years or was otherwise 'protected'.⁵⁻⁷

In the intervention group follow-up for abnormal smears was adequate for 85% of the women compared to 73% in the control group. In the intervention group 4% of the women with abnormal smears were lost to follow-up compared to 13% in the control group.⁷

The positive results of the intervention project in terms of attendance and efficiency were also reached and even slightly improved in this regional implementation project.

The lower attendance rate was compensated for by a higher rate of women with medical reasons not attending.

This can be expected when screening activities increase.

The 'protection rate' was comparable to the intervention project. The variation in attendance rates between the general practices can partly be explained by differences in previous screening activities. As a consequence, the percentage of women who were excluded from invitation for screening because they had had a recent smear taken varied per practice.

But the differences in attendance were also caused by differences in the intensity of reminders: in 13 of the 30 general practices a second reminder by phone or in person during a surgery hour followed after the first reminder.

The experience gained from this implementation project are useful for the new set-up of the screening programme for cervical cancer. It fulfils almost all conditions for a regional plan. In 1996 the project continues, funded by the EC (Europe Against Cancer). As of 1997 the new set-up of the cervical cancer programme will begin. Agreements are being made on continuing and extending of this regional general practice-based call system.

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CHAPTER 7

FEASIBILITY OF COMPARING RISK PROFILES FOR CERVICAL CANCER BETWEEN PARTICIPANTS AND NONPARTICIPANTS IN A SCREENING PROGRAMME

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Abstract

Objective – Feasibility of comparing risk profiles by questionnaire of participants and non-participants in a cervical screening programme:

- does asking information on sexual behaviour by means of a questionnaire lead to high non-response?
- is the non-response selective (related to participation in the screening) and if so how can we limit this.

Design – A postal survey on risk factors for cervical cancer, including sexual behaviour, in a group of participants and nonparticipants.

Setting – Two villages, Wijchen and Beuningen, situated near Nijmegen in the Netherlands.

Subjects – 139 participants and 99 nonparticipants in the national screening programme in 1989 or 1990.

Results – Overall, the response to the questionnaire was high: 83%. Collecting the questionnaire by asking the women to return it by mail in a stamped addressed envelope and one reminder by phone showed a response rate of 79%. This response was selective: 93% of the participants in the screening responded and 61% of the nonparticipants. Collecting them personally showed a extremely high response of 96% which was not selective.

Only 3 respondents did not answer the questions about sexual behaviour.

Main conclusion – Obtaining information on sexual behaviour by questionnaire is feasible.

– Selective response can be limited by an extremely high response rate which can be achieved by collecting of the questionnaires personally.

Introduction

In 1989 a nationwide screening programme for cervical cancer was started in The Netherlands. Every three years women aged 35 to 54 are invited for a cervical smear test. They receive an invitation by letter from the Local Health Authority to make an appointment with their GP. The GP takes the smear while the laboratory makes the cytological diagnosis. If the smear is positive, the laboratory makes recommendations to the GP for follow-up.

The effectiveness of a screening programme depends upon a sufficient attendance rate. So far, the response rates to the Dutch national screening programme are disappointing. Local Health Authorities districts who have evaluated response to screening, report overall response rates of approximately 40%. Another crucial point is that the correct women are being screened. Known risk factors for cervical cancer are inversely related to the participation in screening programmes.¹⁻³

The low participation rate and the question whether the 'high-risk' women are reached with this national call system were motives to set up an intervention-study in which GPs are more involved in the call system. Preliminary results of this study showed a 15% higher participation rate for a general-practice-based call system than to the national call system.⁴

In order to evaluate whether the 'high-risk' women participate in the screening, a questionnaire was designed to compare risk profiles between participants and nonparticipants. Two

problems are to be expected by collecting information on risk factors in this evaluation:

1. High non-response. The identification of women with a higher risk of cervical cancer requires, next to information on smoking,⁵⁻⁷ intimate knowledge of sexual behaviour, since the most important risk factors appear to be related to sexual behaviour.⁸⁻¹⁵ As in other settings,¹⁶ the question emerged: Is the collection of such sensitive data acceptable to women?
2. Selective response. Women who do not participate in cervical screening are less likely to respond to a questionnaire. If this selective response is related to risk for cervical cancer, this will bias the results.

For these reasons we carried out a pilot study in which the questionnaire was tested under participants and nonparticipants in the Dutch screening programme. The key question of this study was: does selective response appear and if so how we can limit it.

Methods

Study population

The study took place in two villages situated near a city and included all 238 women aged 35-54 who were invited for cervical screening in 1989 or 1990, of whom 139 (58%) participated and 99 (42%) did not participate in the screening. Participation in the screening was determined on the basis of information from the regional laboratory.

The questionnaire

A postal questionnaire was conducted. It included questions about age, sexual behaviour (number of sexual partners ever, age at first intercourse), smoking habits and medical reasons for nonparticipation.

In order to study the effect on the response two methods of collecting the questionnaires were used. Of the 238 women, 50 were randomly selected for a more direct collecting method.

Collecting method 1 (n=50).

The women received the questionnaire with an introductory letter by mail. The questionnaires were collected by the researchers personally on a specific date and at a specific time, about which the women were informed. The women also could return the questionnaire by mail in a stamped addressed envelope. If a woman was not at home on the specific date she was phoned for an another appointment or asked to return the questionnaire.

Collecting method 2 (n=188).

The women received the questionnaire with an introductory letter by mail. They were asked to return it in a stamped addressed envelope. Non-responders received a postal reminder. If a woman still did not respond, a second reminder followed by phone.

There were no important differences in age and participation rate in the screening between these two groups of women.

Table 1 *Response rates for the two different collecting methods*

	No.	%	[95%CI]
Method 1 (N=50)			
– returned before collecting date	35	70%	
– collected on collecting date	9	18%	
– returned after reminder-call	3	6%	
– collected after reminder-call	1	2%	
total response	48	96%	[91-100]
Method 2 (N=188)			
– returned before reminder	117	62%	
– returned after first reminder (letter)	22	12%	
– returned after second reminder (call)	10	5%	
total response	149	79%	[73-85]
Total response method 1 + 2 (n=238)	197	83%	

Table 2 *Questionnaire response rates for participants and nonparticipants of the screening programme*

	Response to questionnaire		
	No.	%	[95%CI]
Method 1			
– participants (n=31)	30	97%	[91-100]
– nonparticipants (n=19)	18	95%	[85-100]
Method 2			
– participants (n=108)	100	93%	[88-97]
– nonparticipants (n=80)	49	61%	[50-72]
Total			
– participants (n=139)	130	94%	[90-98]
– nonparticipants (n=99)	67	68%	[59-77]

The average age in the first group (method 1) was 42 and in the second group (method 2) 44. The participation rates in the screening programme was 62% and 57%, respectively.

Risk profiles

Women who did not answer the questions about sexual behaviour were excluded from this analysis.

Women could indicate in the questionnaire that they were already ‘protected’ for cervical cancer before screening, because they had recently had a smear or had undergone total hysterectomy. These ‘protected’ women were, in fact, not eligible for screening and therefore their risk profiles are presented separately. The risk profiles of the ‘unprotected’ participants and nonparticipants, who were eligible for screening, were compared.

Causality was no criterion for including a factor in the risk profile, because the objective was to identify women with a higher risk. The following factors, which in the available literature are clearly and consistently associated with cervical cancer, have been included in the risk profiles: risk from sexual behaviour and smoking. Risk from sexual behaviour is defined as having had three or more sexual partners and/or the first intercourse before the age of 21.^{8,11,12,13}

Results

Response to the questionnaire

A total of 197 women responded to the questionnaire (83%).

Method 1 showed a response rate of 96% (Table 1). No fewer than 70% returned the questionnaire by mail before the collecting date.

Of the 139 women who had taken part in the screening, 130 responded to the questionnaire (94%) and of the 99 nonparticipants, 67 women responded (68%) (Table 2). Collecting method 1 showed hardly any difference in response rates between participants and nonparticipants. Collecting method 2, however, showed a response rate of 93% for the participants and 61% for the nonparticipants.

Only 3 of the 197 women did not answer the questions about sexual behaviour.

Risk profiles

The three women who did not answer the questions about sexual behaviour were excluded from this analysis.

74 women were not eligible for screening, 43 who nevertheless did participate and 31 nonparticipants.

There were 84 participants and 36 nonparticipants who were ‘unprotected’ before screening. The two risk factors were presented together more often (39%) in the ‘unprotected’ nonparticipants than in the ‘unprotected’ participants (20%). The difference was not statistical significant. On aggregate, however, there was no difference between ‘unprotected’ participants and nonparticipants in the number of women with one or both risk factors for cervical cancer (Table 3).

Table 3 *Number of risk factors, by 'protection' before screening and participation in screening*

	N	no risk factor No. (%) [95%CI]	one risk factor: either smoking or sexual behaviour* No. (%) [95%CI]	two risk factors: smoking and sexual behaviour* No. (%) [95%CI]
'unprotected' before screening				
– participants	84	28 (33%) [23-43]	39 (47%) [36-58]	17 (20%) [11-29]
– nonparticipants	36	12 (33%) [18-48]	10 (28%) [13-43]	14 (39%) [23-55]
'protected' before screening				
– participants	43	15 (35%) [21-49]	21 (49%) [34-64]	7 (16%) [5-27]
– nonparticipants	31	15 (48%) [30-66]	8 (26%) [11-41]	8 (26%) [11-41]

* risk by sexual behaviour = age first sexual intercourse < 21 or number of sexual partners 3 or both.

Discussion

In this pilot study the answer to the question, whether collecting such sensitive data is acceptable to women, was positive: almost all women answered the questions about sexual behaviour and the overall response rate was high (87%). It is inevitable, of course, that there are women who will not answer these questions completely honestly.

A major problem with this kind of study is the risk of a selective response which could lead to bias. Women who do not participate in screening may also be less likely to respond to the questionnaire. This could be confirmed in this study. Selective response can be limited by getting an extremely high response rate.

In case-control studies on risk factors for cervical cancer, data on sexual behaviour have mostly been gathered by personal interviews. Response of the controls in this studies varied from 70 to 98%.^{7,9,11-15,17,18}

Although in general personal interviews give higher response rates, we chose a postal survey because answers to sensitive questions are more valid in postal surveys than in interviews.¹⁹

A postal questionnaire on sexual behaviour in a study in Denmark showed response rates of 85-88 per cent.²⁰ In our study the response for collecting method 2 was 79%. However, selective response appeared with this method. Therefore an important result of this pilot study was the extremely high response (96%) for the personal collecting method. There was no difference in response between participants and nonparticipants of the screening programme.

Another problem we met in this study was the relatively high proportion of women who were already protected before screening. Risk profiles were compared for 'unprotected' participants and nonparticipants, because we wanted to answer the question whether the 'high-risk' group of women who have to be reached by the call system participate in the screening. Women not eligible for screening were excluded from the risk analysis retrospectively. This unnecessary data collection is inefficient and unethical.

The numbers in this study are too small to draw conclusions on differences in risk profiles between participants and nonparticipants. In addition, the selective response could have biased the results.

A larger-scale study is planned to provide more insight into the risk profiles of women who participate and women who do not. For that study two conditions have to be fulfilled. First, to avoid selective response a very high response (about 90%) is necessary. Therefore the questionnaire will be personally collected. Since in the present study 78% of this group returned the questionnaires by mail, this method did not take a lot of extra time and might be well feasible in practice.

Second, for the efficiency of the study, the study population should be restricted to unprotected women.

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CHAPTER 8

GENERAL PRACTITIONER BASED SCREENING FOR CERVICAL CANCER: HIGHER PARTICIPATION OF WOMEN WITH A HIGHER RISK?

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Summary

Background – For cervical cancer screening to be effective it is essential that women with a high risk for cervical cancer participate. There are indications that in mass screening campaigns a substantial number of the non-attenders are high-risk women.

Objective – The aim of this study was to test the hypothesis that a personal invitation for screening by a woman's own general practitioner (GP) achieves a higher attendance of women with an elevated risk for cervical cancer.

Setting – Two general practices and the Local Health Authority screening programme for cervical cancer, Nijmegen, The Netherlands.

Design – Attendance rates of women with an elevated risk for cervical cancer were compared for two invitation strategies: (1) invitation by the woman's own GP and (2) invitation by a national call system through the Local Health Authority. Data on risk profiles were gathered by questionnaire.

Subjects – 238 women eligible for screening who were invited by their GPs (GP group) and 235 women eligible for screening invited by the Local Health Authority (control group) in 1992.

Results – The personal invitation of the GP achieved an 18% higher overall attendance, and a 28% higher attendance of women with greater risk because of sexual behaviour and smoking.

Conclusion – Greater involvement of the GP in invitation women for cervical cancer screening results in a higher attendance, particularly in women with elevated risk, compared to less personal national call system.

Introduction

The participation rate is a critical factor in cervical cancer screening programmes. In addition to the concerns of overall attendance, there is the question of whether the right women are screened. It has been reported that known risk factors for cervical cancer are inversely related to participation in screening programmes.^{1,2,3} For non-participants in screening, the incidence and mortality rates of cancer of the cervix were higher.⁴

A national screening programme for cervical cancer was started in the Netherlands in 1989.⁵ In this programme all women aged 35-54 are invited for a cervical smear every three years. The municipal population registers are used to identify women to be invited, and the Local Health Authority then sends the invitation. This invitation requires, that each woman makes an appointment with her general practitioner (GP), who takes the smear.

The attendance rates of 40% to 50% for this nationwide screening programme are disappointing. Major problems have been identified in monitoring attendance and sending reminders, as different authorities invite the women and take the smears.⁶ In addition, an invitation from a Local Health Authority is rather impersonal. Against this background a project was undertaken in the region of Nijmegen to involve GPs in identifying and inviting women for

screening. This personal invitation from the GP resulted in a 12% increase in the screening attendance rate, which was increased an additional 9% if a reminder was sent, as compared to the national call system.⁶

However, this does not address the question of participation of women with a higher risk for cervical cancer. Results from pilot screening programmes have shown that more cervical abnormalities were found in smears taken from women who attended screening after receiving a reminder⁵. This implies that, with some extra efforts, more women in the high-risk group were reached. A personal invitation and/or reminder from their own GPs may provide such incentive. This would contribute to the effectiveness of the screening programme. The aim of this study was to test the hypothesis that a personal invitation for screening by the womens' own GPs achieves a higher attendance rate of women with an elevated risk for cervical cancer, compared to the national screening programme.

Methods

Design

Attendance rates for screening and risk profiles for cervical cancer were compared between: (1) invitation by the woman's own GP and (2) invitation by a national call system through the Local Health Authority. Data on risk profiles were gathered by questionnaire and data on attendance for screening were gathered from the registers of the pathology laboratory. The study was part of an overall study to compare GP-directed and Local Health Authority-directed screening for cervical cancer.^{6,7,8}

Study population

The study population for this study consists of two groups of women who had been invited for screening for cervical cancer in 1992: (1) women invited by two GPs (GP group), and (2) women invited by the Local Health Authority (control group).

The GP group included all women who were invited for screening in 1992 (n=238) and registered at the two general practices in Nijmegen participating in an intervention project. The control group consisted of a random sample of 235 women, invited for cervical screening in 1992, who were living in Nijmegen and were registered with practices not participating in this GP-based call system.^{5,21}

The intervention project started in 1990 in the region of Nijmegen; ten general practices introduced a GP-based call system for cervical cancer. Practices with computerized age-sex registers and which sent the smears to the regional screening laboratory were eligible for to introduce a GP-based call system for cervical cancer to their practice. At the start of this project only 11 practices fulfilled these criteria. Ten of them were willing to participate in the project. None of these practices had taken any prior initiatives to organize cervical cancer screening or had shown any special interest in cervical screening.

Since a criterion for participating in the GP-based call system was computerization, the GP group could be selective, and thereby was not comparable with the control group. The 'early

computerized' practices might have more screening activities, and their patients might therefore be more likely to participate because they are used to these activities. A regionally conducted survey, however, showed no relation between 'computerization' and 'screening activities within the practice' and 'attitude to screening programmes/activities'.

Since previous screening in the region showed that attendance for screening was different for rural regions compared to urban regions, this study was restricted to the urban region: the two GPs involved in the GP-based call system and controls in the city of Nijmegen.

Because the risk status and participation is only relevant for those 'unprotected' against cervical cancer, women were excluded from the study if they had had a cervical smear within the past year or a total hysterectomy, or if they were under follow-up care for previous cytological abnormalities. Information on the medical status was gathered from the register of the pathology laboratory and the questionnaire.

Risk factors/indicators

Based on the available literature, the following factors were identified as carrying a higher risk for cervical cancer:⁹⁻¹⁸

- marital status: unmarried or divorced
- low level of education
- low level of education of the partner
- age at first intercourse < 18 years
- number of sexual partners (lifetime) > 2
- smoking

It is thought that with these, most risk factors were taken into account in identifying women with a higher risk for cervical cancer. Known risk factors not taken into account were exposure to HPV and sexual behaviour of the male.¹⁹ Exposure to HPV was unknown and not measurable by questionnaire. The postal questionnaire was addressed only to the women; we thought that questions on sexual behaviour of the male might be too intimate or answers might be unreliable.

No doubt the chosen profile is not the most optimal predictor of women with the highest risk for cervical cancer. But even when the used risk profile may not be the 'best' profile or risk score, it indicates in our view a group of women with elevated risk for cervical cancer.

Recent studies in the UK have presented promising results of a risk score to predict cervical neoplasia.^{20,21,22} This score includes the education level, smoking status, oral contraceptive use, and number of sexual partners.

The questionnaire

A postal questionnaire was conducted. It included questions on education level, marital status, sexual behaviour, and smoking. The questionnaire was designed and tested in a pilot study, with special attention to the overall response rate (because of the intimacy of questions on sexual behaviour) and the selectiveness of response; non-participants of screening might be less likely to respond to the questionnaire. The pilot study demonstrated that the questions were acceptable and that a high response rate could be achieved by a direct-collecting

method.²³ Therefore the same questions and the same direct-collecting method were used in this study.

The women received the questionnaire by mail. The questionnaires were personally collected by researchers on a pre-arranged date, but the women could also return the questionnaire by mail in a pre-addressed envelope. If a woman was not at home on the appointed date, a reminder was left in her mailbox with a request to return the questionnaire by mail.

Analysis

The risk profiles were grouped based on the strongest and most consistent risk factors available in the literature at the time we designed the study, as:⁹⁻¹⁸

1. no smoker and no risk due to sexual behaviour
2. risk due to either sexual behaviour or smoking
3. risk due to both sexual behaviour and smoking

The attendance rate and risk status of the GP group were compared with the control group. Since there is a known effect on attendance with the invitation by the GP⁶, the outcome measure was 'the additional difference'. The difference in attendance between the GP group and the control group was calculated for every risk factor or risk indicator, and from this the overall difference in the participation rate between GP-invited and Local Health Authority-invited groups was inferred. A positive value indicates that there is an additional gain in attendance for that risk. Alternatively, a negative value indicates that the GP invitation results in a smaller increase in attendance in the presence of that risk.

The GP group and control group were comparable for rate of urbanisation because the study was restricted to the city, but there were some differences in distribution of other factors that are known to be related to attendance for screening. The women of the control group were somewhat more often divorced. The GP group had relatively more women with an average education level, while the control group included more women with low and high education levels. And the women of the control group were a bit more often smokers.

Correction for possible confounding of these factors was not possible because of the risk of overcorrection. During analysis the factors showed to be strongly related. Education level and marital status indicate the risk factors of the risk profiles. Higher education is related to higher risk because of sexual behaviour, and lower education with higher risk due to smoking. Marital status indicates sexual behaviour, mainly the number of sexual partners. Stratification on these indicators thereby also leads to some stratification of these risk factors, and thus becomes not interpretable.

Results

The response

The questionnaire was sent to 473 women (238 in the GP group and 235 in the control group). For these women the attendance rate for the screening was 64% in the GP group and 49% in the control group.

349 women (74%) responded to the questionnaire (75% in the GP group and 74% in the control group).

This and other studies^{22,23} showed that self-reporting by women on intimate questions is feasible and acceptable.

A selective response (more respondents among the participants of the screening), however, could not be avoided, but this occurred equally in both groups. The response among the attenders was higher (83%) than among the non-attenders (62%). This 'selective response' occurred both in the GP group (82% vs. 62%) and in the control group (84% vs. 62%). Consequently, it seems unlikely that the findings – higher participation in cervical cancer screening of women at the highest risk for cervical cancer, when invited by their own GP – have been biased.

Based on the data from the questionnaire, 60 women were excluded from analysis because they were not eligible for screening.

Because of the selective response the attendance rate for the screening was 86% in the GP group and 68% in the control group on which data were analyzed, a difference of 18%.

Table 1 *Distribution of risk factors in the GP and control group*

		GP group	Control group
Marital status	– unmarried/divorced	85%	65%
	– married	15%	35%
Educational level	– low	31%	30%
	– moderate	50%	22%
	– high	18%	48%
Age at first intercourse	< 18 yr	38%	33%
	18 yr	62%	67%
Number of sexual partners	> 2	70%	41%
	2	30%	59%
Smoking	– yes	35%	42%
	– no	65%	58%

The GP group and control group were not comparable on all factors. Table 1 presents the distribution of the measured risk factors in the two groups.

Attendance-specific risk groups

Table 2 presents the attendance of screening according to the risk factors and risk indicators. For each subgroup the attendance rates in the GP group were higher than in the control

Table 2 *Attendance rates for women with a specific risk factor or indicator for cervical cancer for the GP group and control group*

	GP group	Control group	Difference	Additional difference
	N attendance	N attendance		
Risk				
Marital status				
– unmarried\divorced	22 77%	50 62%	15%	–3%
– married	125 87%	92 71%	16%	–2%
Educational level				
– low	46 85%	42 62%	23%	5%
– moderate	74 88%	31 71%	17%	–1%
– high	27 81%	67 70%	11%	–7%
Educational level partner				
– low	33 94%	30 53%	41%	23%
– moderate	70 86%	34 74%	12%	–6%
– high	36 86%	67 76%	10%	–8%
Age at first intercourse				
<18 yr	55 87%	47 70%	17%	–1%
18 yr	90 84%	94 67%	17%	–1%
Number of sexual partners				
> 2	44 91%	78 64%	27%	9%
2	101 83%	62 73%	10%	–8%
Smoking				
– yes	52 85%	59 59%	26%	8%
– no	95 86%	83 73%	13%	–5%

group. For women with a low educational level, or whose partner had a low education, for women with more than two sexual partners (during their lifetime), and for smokers there was an additional difference in attendance, ranging from 5%-23%, indicating that GP invitation yielded extra participation for the screening for these higher risk groups. Negative values in the additional differences were observed for women with a first sexual intercourse at a young age, and for unmarried and divorced women. This indicates that the GP invitation for screening triggered a lower extra response in these women, but still a higher compared to the women with this elevated risk in the control group.

Risk profiles

In 28% of the women there were no risk factors or risk indicators present (34% GP group, 23% control group). In 60% there was a risk due to sexual behaviour (53% GP group, 66% control group), and in 38% due to smoking (35% GP group, 42% control group). A combined sexual behaviour and smoking risk was established in 27% of the women (23% GP group, 31% control group).

Elevated risk coincided with a 28% higher attendance rate in the GP group compared with the control group, both for sexual behaviour-related risk and smoking-related risk (Table 3). This means there was an additional 10% screening participation in this group, in addition to an average 18% difference in the GP group compared to the control group.

Discussion

A major problem in cervical screening is the noncompliance of women with higher risk for cervical cancer. In most programmes with low coverage rates the women at greatest risk are reached least often. With the general practice-based call system this barrier was reduced,

Table 3 *Attendance rates for women with different risk profiles for cervical cancer for the GP group and control group*

Risk profile	GP group attendance		control group attendance		difference	additional difference
	No.	%	No.	%		
Not smoker and no risk due to sexual behaviour	49	84%	32	78%	6%	-12%
1 risk factor*	62	87%	64	70%	17%	-1%
2 risk factors**	34	85%	44	57%	28%	10%

* risk due to either sexual behaviour or smoking

** risk due to both sexual behaviour and smoking

resulting in a higher attendance for screening overall, and even particularly in women with elevated risk, compared to a national call system.

Previous studies have already shown a positive effect on attendance of a GP-based call system.⁶ This study showed that this positive effect of the personal invitation of the GP has an extra effect in all subgroups of risk including women with higher risk. Even without an additional effect within this group, the GP-based call system reaches more women with higher risk. The effect, however, was even greater in most subgroups with elevated risk. For example, the attendance was higher in the GP-group for all levels of education, but the effect was the highest in the low education level group. The same was seen in the risk profiles according to sexual behaviour and smoking. In all subgroups, with no risk factor, one risk factor, or both risk factors, the attendance was higher in the group invited by their GP. In the high risk group, with risk by smoking and sexual behaviour the effect was the greatest.

Since the initiation of the national mass screening programme for cervical cancer in The Netherlands some problems have become evident which might reduce its potential benefits. The hypothesis that more involvement of the GP reduces some of these barriers proved to be true. Thus, it can be concluded that GP involvement in cervical cancer screening results in higher participation⁶, more effective follow-up⁷ and, through better selection (with the possibility of excluding women not eligible for screening), more efficient use of facilities⁶. To this can be added the potential of reaching women with higher risk of cervical cancer, and therefore with the greatest need for screening.

The screening attendance rates for higher-risk women in the GP-based call system were probably greater because of the involvement of their GPs in the cervical screening. Each woman received a personal invitation to screening, signed by her GP, as well as personal reminders if necessary. In addition, the commitment of the GPs and other practice staff members might have led to extra efforts to make the screening a success, for example, by urging women visiting the surgery for other reasons to attend to the screening.

In The Netherlands most patients have the same GP for a long time, allowing a bond to develop. The GP has contact with almost all of his patients at least once every two to three years. This relationship is probably an extra incentive for high-risk women to participate in screening. In addition, other studies have shown that more direct approaches to screening achieves greater compliance of high-risk women. For instance, public screening and workplace screening programmes in the UK attracted more women of a lower social class.²⁴

In conclusion, a higher level of involvement by GPs in cervical cancer screening is recommended, as it will contribute to a more effective screening programme. Specially, since greater GP involvement might compel more higher-risk women, who historically have low screening participation rates, to attend cervical cancer screening programmes.

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CHAPTER 9

THE EFFECT OF THE FAMILY PHYSICIAN ON IMPROVING FOLLOW-UP AFTER AN ABNORMAL PAP SMEAR

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Abstract

Objective – The aim of this study was to assess the effect of the family physician on improving compliance with follow-up of abnormal smears in cervical cancer screening.

Design – Observational study.

Setting – Two Regional Health Authority districts in the east of the Netherlands.

Study participants – Family practices with a national call system for cervical cancer screening and family practices with a family-practice-based call system. In a number of practices the family physicians had introduced a fail-safe system for follow-up.

Main outcome measures – Follow-up of women who participated in the first screening round and in whom a cytological abnormality had been diagnosed in the first smear. Criteria for adequate follow-up were defined with regard to the severity of the cytological abnormality.

Results – The overall compliance with follow-up in the study-group was 88%. The study showed a strong relationship between involvement of the family physician and compliance with follow-up. The compliance in practices that had a fail-safe system for follow-up was 93% compared to 82% in the practices without a fail-safe system. The highest follow-up was found in practices involved in the family-practice-based system.

Key words: screening, cervical cancer, call system, follow-up, family-practice-based call system, family physician, organisation, computerization.

Introduction

Mortality from cancer of the cervix can be reduced by cytological screening. The Nordic countries of Europe with carefully organized screening programmes, have shown a sharp reduction both in incidence and in mortality from cervical cancer since the mid-1960s, when mass screening started.¹ The crucial question for the success of cervical cancer screening is one of organization, to ensure high participation, an adequate follow-up of cytological abnormalities and good smear taking.

In The Netherlands, a nationwide screening programme for cervical cancer was started in 1989. Every 3 years, all women aged between 35 and 54 years are invited for a cervical smear. In this nationwide programme the Regional Health Authority invites the women and the family physician takes the smears. Under these conditions, monitoring of and responsibility for participation is a major problem. Thus far, the attendance rate of this nationwide screening programme have been disappointing, ranging from 40 to 50%.

Another problem is the responsibility for the follow-up of women with preinvasive cytological abnormalities. The laboratory will advise on the follow-up actions, which have to be performed by the family physician. Again, the responsibility for supervision is not regulated. Compliance with follow-up of the women who participated in the nationwide programme has not yet been investigated.

The quality of cervical smears taken by family physicians in the national screening pro-

gramme has been evaluated in the region of Nijmegen. The results of this study show that the quality of smears taken by family physicians has improved since the start of the national screening programme.²

A system in which the family physician will be responsible for invitations to receive a PAP smear, is an option for improvement of the screening programme. Therefore, in 1989 an intervention study with a family-practice-based call system started in the Regional Health Authority district in the east of The Netherlands, to evaluate the effect of this call system on attendance rate and compliance with follow-up. The intervention group consisted of nine computerized family practices, women from these practices were invited for cervical cancer screening by a personal letter from their own family physician. The control group consisted of the other practices in the region without a family-practice-based call system. In these practices the women were invited by the Regional Health Authority (national call system).

The family-practice-based call system resulted in a higher attendance rate than the national call system. The attendance rate in the intervention group was 55% compared to 43% in the control group. A reminder in the family-practice-based call system increased the attendance rate by an additional 9%.³

This paper deals with the compliance with follow-up. First we assessed the extent of compliance with follow-up of cytological abnormalities among all women participating in the screening in two Regional Health Authority districts in the east of The Netherlands. Secondly we evaluated the effect of the involvement of the family physician on compliance with follow-up. Our expectation was that involvement of the family physicians in a family-practice-based call system for invitations to receive PAP smear, would increase their involvement in ensuring adequate follow-up.

Methods

Compliance with follow-up

As data on the smear results were collected from the regional cytological laboratory, this study was confined to the family practices that sent their smears to the Nijmegen laboratory (86 family practices).

Included in the follow-up study were all women registered in these practices who participated in the first screening round (1989-1991) and in whom a cytological abnormality had been diagnosed in the first smear. This selection was made by the regional laboratory. At the laboratory, information was obtained about the age of the woman; her marital status, the family physician with whom a woman was registered and about PAP smear results with recommendation for follow-up.

Criteria for adequate follow-up were defined with regard to the severity of the cytological abnormality. The national screening programme includes clear guidelines for the follow-up of abnormal smears.⁴ In case of a positive smear the laboratory gives recommendations to the family physician for follow-up. The interval at which a repeat smear was recommended depended on the classification of the smear: for mild and moderate dysplasia a first repeat smear was recommended after 3 months. For severe dysplasia a first repeat smear was

recommended after 1 month or the women were referred to a gynaecologist. Women with a cytological diagnosis consistent with carcinoma in situ or invasive cancer had to be referred for histological analysis.

Women who completed the recommended follow-up procedures within reasonable margins of the indicated interval were classified as "optimal follow-up". Women who completed the recommended follow-up but after the reasonable interval were classified as "suboptimal follow-up". Women who failed to return, or only returned after a period of 12 months were defined as "lost to follow-up" (Table 1).

Data about compliance with follow-up were obtained from the national data bank of the pathology laboratories. All women were traced for a minimum of 12 months after the date of the abnormal PAP smear. Information was collected on all recommended follow-up procedures, whether they were performed, and, if so, on which date.

Involvement of the family physicians

Women registered in nine family practices of these regions received an invitation for cervical cancer screening from their family physician (family-practice-based call system). Women registered in the other 77 family practices of the regions were invited by the Regional Health Authorities (national call system).

In all practices the family physician took the smears. In a number of the practices the family physicians had introduced a system for monitoring and surveillance of follow-up of women

Table 1 *Definition of follow-up*

	N	%	optimal follow-up (interval to repeat examination in months)	suboptimal follow-up	lost to follow-up
Recommended interval					
1 month or after short period	86	16.8	3	4-12	>12
after treatment of inflammatory changes	4	0.8	6	7-12	>12
3 months	320	62.6	5	6-12	>12
6 months	48	9.4	9	10-12	>12
referral for histological analysis	35	6.9	3	4-12	>12
1 month or referral for histological analysis	18	3.5	3	4-12	>12

with cytological abnormalities, a fail-safe system. Data about the presence of a fail safe system in the nine family practices with the family-practice-based call system were known from the intervention study. In the 77 family practices with the national call system these data were known in 45 practices from a postal survey conducted in part of the study-region.⁵ No data regarding monitoring and surveillance were known for the remaining 35 practices. Therefore these practices were excluded from analyses concerning involvement of family physicians and compliance with follow-up.

Analysis

In an univariate analysis the relation was assessed between known characteristics of the women (age, marital status and PAP smear results) and compliance with follow-up.

To evaluate the effect of the family physician's involvement the follow-up of abnormal smears was compared between practices with and without a fail-safe system, and practices with and without the family-practice-based call system.

A logistic regression was made to correct for potential confounders on the involvement effects. The involvement effects were defined as the effect of a fail-safe system (both in the practices with the family-practice-based call system and in those with the national call system) and the effect of involvement in a call system. For this analysis the outcome measure was dichotomized into women with optimal follow-up versus women with suboptimal follow-up or without follow-up. The involvement effects and all significant characteristics of the women were included in a stepwise logistic regression model: a fail-safe system, a family-practice based system, age 43 years and younger, severe dysplasia or higher. Only variables that met the 0.15 significance level are included in the model.

Results

Initially 586 women were selected on the basis of a report of cellular abnormality. Seventy-five women were excluded because of a previous abnormal smear. The study therefore included 511 women. Smears were classified as mild dysplasia (n=335; 66%), moderate dysplasia (n=77; 15%), severe dysplasia (n=56; 11%) , carcinoma in situ (n=41; 8%) and (micro) invasive cancer (n=2).

Overall, 76% of the population was classified as optimal follow-up; 12% as sub-optimal follow-up and 12% as being lost for follow-up. Women who failed to comply with follow-up were more likely to be older and to have a less severe degree of cytological abnormality than women who returned for follow-up (Table 2). There was no relation between marital status and compliance with follow-up.

For further analysis 205 women registered in 35 practices with the national call system were excluded. No data regarding monitoring and surveillance of follow-up were known for these

Table 2 Follow-up according to age, marital status and PAP smear results

	N		optimal follow-up		suboptimal follow-up		lost to follow-up		X ²	P value
	N		N	%	N	%	N	%		
Age										
43 and under	281	225	80.1		31	11.0	25	8.9		
44 and over	230	162	70.4		33	14.4	35	15.2	6.96	0.031
Marital status*										
married	377	283	75.1		49	13.0	45	11.9		
unmarried	44	32	72.7		6	13.65	6	13.65	0.14	0.935
PAP smear results										
Mild-moderate dysplasia	412	300	72.8		57	13.8	55	13.4		
severe dysplasia or higher	99	87	87.9		7	7.1	5	5.0	9.99	0.007

* 90 women: marital status unknown

practices. The remaining 306 women consisted of 53 women registered with 9 practices with the family-practice-based call system and 253 women registered with 42 practices with the national call system.

All the practices with the family-practice-based call system had a fail-safe system for follow-up. They sent an invitation for follow-up or contacted women who did not respond to recommended repeat smears or histological analysis. In the intervention study the time spent on such a fail-safe system was only 2-3 hours a year.⁶

Of the practices with the national call system 50% also had such a fail-safe system.

There was a relation between involvement of the family physician and compliance with follow-up. The compliance in practices with a fail-safe system was 93% compared to 82% in the practices without a fail-safe system, optimal follow-up was 81% compared to 65%. The highest compliance was found among the women registered with the practices with the family-practice-based call system (Table 3).

Table 4 shows the odds ratios derived from the logistic regression model. The following factors had an independent association with follow-up: severity of initial cytological abnormality and the presence of a fail-safe system for follow-up in the practice. There is no independent effect of the involvement in the family-practice-based call system.

The age of women did not independently contribute to the consistency of follow-up of abnormal smears.

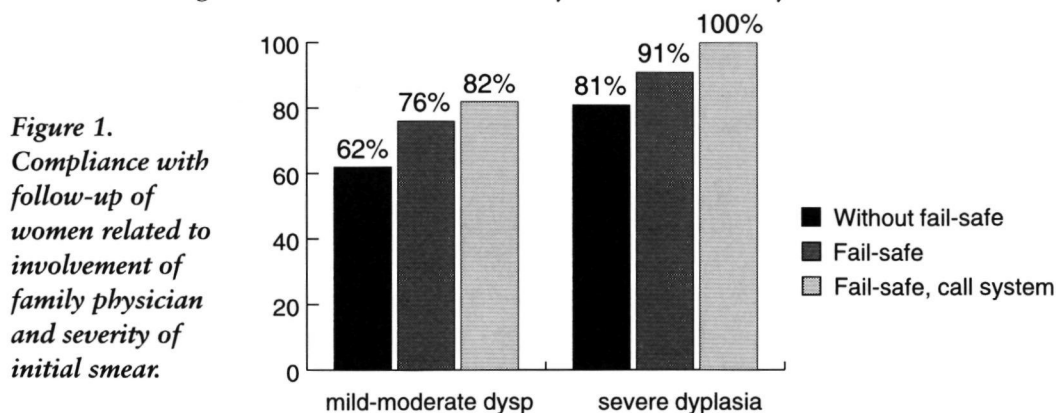
Table 3 Follow-up and involvement of the family physician

	N	optimal follow-up		suboptimal follow-up		lost for follow-up		X ²	P value
		N	%	N	%	N	%		
Practices with a fail-safe system:									
– family-practice-based call system	53	45	84.9	6	11.3	2	3.8		
– national call system	140	111	79.3	17	12.1	12	8.6		
Practices without a fail-safe system:									
– national call system	113	74	65.5	19	16.8	20	17.7	11.45	0.02
total	306	230	75.2	42	13.7	34	11.1		

Table 4 Logistic regression (stepwise logistic regression model with the following variables: a fail-safe system, a family-practice based system, age 43 years and younger, severe dysplasia or higher. Only variables that met the 0.15 significance level are included in the model)

	Partial R ²	model R ²	C (p)	F	Prob>F
1. fail-safe system	0.029	0.029	8.317	9.038	0.0029
2. severe dysplasia or higher	0.024	0.053	2.805	7.518	0.0065

Figure 1 shows the compliance related to the involvement of the family physician with whom a woman was registered as well as to the severity of the abnormality of the initial smear.



Discussion

This study shows that family physicians who are involved in inviting women to participate in a screening programme for cervical cancer, are more successful in obtaining follow-up of abnormal smears than family physicians not involved in the initial screening invitation. Successful follow-up was related to the severity of abnormality of the initial smear as well to the willingness of the family physician to monitor follow-up.

The family practices who had introduced a fail-safe system for follow-up were more successful in compliance with follow-up compared to practices without a fail-safe system. This is true for all women who had a cytological abnormality in the initial smear. However, the differences become even more clear when the women are categorized according to the severity of the abnormality. The fail-safe system had an effect for women with a severe dysplasia as well as for women with a mild/moderate dysplasia in the initial smear (Figure 1).

The highest proportion of compliance with follow-up was found in the practices that were also involved in the call system. To a large extent the effect of the involvement in the call system can be explained by the presence of a fail-safe system in all these practices. We think that the involvement of family physicians in a family-practice-based call system had a stimulating effect on the introduction of a fail-safe system within the practices as well as on the responsibility of the family physician for adequate follow-up.

The compliance with follow-up among the women registered with practices without a fail-safe system was consistent with the results of other studies. Eighty-two per cent of the women returned for follow-up, 65.5% with optimal follow-up. These findings are comparable with, or better than, those from other studies, in which, although the definitions of follow-up varied, compliance was not higher than 60-70%. Elwood et al.⁷ found satisfactory follow-up for fewer than 60% of women diagnosed with cervical abnormalities on PAP smears. Satisfactory follow-up was defined as: gynaecological referral and further assessment or treatment and for mild or moderate cases two consecutive normal smears.

In a study of Mitchell and Medley⁸ 63% of the women with mild to severe dysplasia were rescreened. In a large randomized trial Marcus et al.⁹ showed that nearly 30% of women who had abnormal PAP smears completely failed to return for follow-up.

In this study compliance with follow-up was strongly related to the severity of the initial PAP smear. Among women with severe dysplasia or higher only 5% did not return for follow-up. Among women with mild-moderate dysplasia the percentage lost to follow-up was much higher.

The influence of the severity of the initial abnormality for follow-up in this study was consistent with the results of other studies,^{9,10} but the influence of the woman's age and marital status^{8,9} that have been reported, could not be confirmed.

Several factors will have influenced the results of this study. The introduction of a family-practice-based call system depended on the availability of a computerized system in the practice. Placing practices in a family-practice-based system was therefore not random. In

these practices the family physicians and their staff were actively involved in the call system. Though there were no indications^{3,5,11} that this group initially had a different attitude to cervical screening or towards an active role in prevention in general, such a selection bias cannot be ruled out. This may have resulted in the introduction of a 'fail-safe' system, which all practices with the family-based-call system introduced on their own initiative. The principles of the family-practice-call system was known to the non-participating practices in the region, and this, again, may have influenced their attitudes. This may have resulted in the implementation of a self-initiated 'fail-safe' system in some of the practices with the national call system.

Follow-up can be improved by reminders and giving better information to the women. In a study of Michielutte¹⁰ in which non-compliant women were sent one or two reminders, the follow-up was 83%. A positive effect of reminders was also found in Mitchell and Medley's study. A reminder letter increased follow-up from 63 to 85%.⁸ Another attempt to increase compliance was made in the intervention study of Marcus et al., in which a personalized follow-up combined with targeted information had a positive impact on follow-up.⁹

The laboratory can play an important role in monitoring follow-up. During the pilot-programmes carried out in three regions in The Netherlands from 1976 to 1986,^{12,13} the laboratory initiated a fail-safe procedure to ensure that family physicians did not forget to repeat smears after a recommended delay. A linking of the computerized laboratory to the computerized general practice could further facilitate the supervision of follow-up of abnormal smears. In the period of this study the regional laboratory monitored the compliance of women with severe dysplasia. This surveillance undoubtedly contributed to the high compliance within this group. Thereby women with a more severe degree of cytological abnormality were more likely to return for follow-up.

Even under these relative good circumstances the found extra value of a fail-safe system within the practice stands out clearly.

This study showed that the introduction of a fail-safe system for follow-up in the family practice resulted in a higher compliance with follow-up.

The best results of follow-up were found in the practices that were also involved in the call system. We think that the involvement in the family-practice-based system also increases the responsibility for follow up. All these practices had introduced a fail-safe system and were conscientious in the execution of this system.

In the nationwide screening programme the follow-up can be improved by a higher level of involvement by family physicians. One option is the introduction of a family-practice-based call system. This model appears feasible on a larger scale in The Netherlands and in other countries where data from practice lists are available.³ But in all practices where family physicians take the smears for screening they are also responsible for adequate follow-up. Therefore the government has to stimulate the introduction of a fail-safe system for follow-up in all these practices. The introduction of such a system is simple and does not take much time.

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CHAPTER 10

CELLULAR COMPOSITION OF CERVICAL SMEARS TAKEN BY GENERAL PRACTITIONERS

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Abstract

The quality of the cervical smears taken by general practitioners, and also by some practice assistants, of the Dutch Screening Programme in the region of Nijmegen was evaluated.

Of 18,398 preventive cervical smears taken by GPs in this region, 437 (2%) were diagnosed as “class” 0 and 2,907 (16%) smears did not contain endocervical cells (EC-). The quality of the smears per general practitioner varied enormously.

The percentage of smears without endocervical cells taken by six practice assistants was 18. During the screening period the percentage of smears without endocervical cells taken by GPs decreased from 19 (1989) to 14 (1992).

In february 1990 the six practice assistants followed a theoretical and practical course on cervical smear-taking. Remarkable was the decrease in the percentage of smears without an endocervical component from 25% in 1990 to 13% in 1991.

The quality of smears taken by GPs would improve if the general practitioner had more experience in smear-taking. We recommend to offer GPs the opportunity to take practical training courses in smear-taking, just as the practice assistants in this project.

Introduction

Well-organized screening can reduce the incidence of, and mortality from, cancer of the cervix.^{1,2,3,4,5}

After pilot programmes for cervical cancer screening in three regions from 1976 to 1986,⁶ a nationwide screening programme was started in the Netherlands in 1989. Every three years, all women aged between 35 and 54 received an invitation, by letter from the Regional Health Authority, to make an appointment with their general practitioner. Women were identified by the Registry Office. In the pilot programmes cervical smears were taken by specially trained paramedical workers. In the national programme cervical smear-taking was allocated to the general practitioners. The question arose: what is the quality of smears taken by general practitioners?

Cytological abnormalities were diagnosed with a descriptive reference to the expected histological abnormality with a class grading from 0 to 5. A cervical sample is inadequate if the sample cannot be evaluated for the presence of abnormalities because of excessive blood, inflammation or inappropriate fixation (“class 0”). There is no consensus, however, “what” constitutes an adequate sample. Interest has focused on the endocervical component. Studies on the significance of an endocervical component have shown opposite results.^{7,8,9,10} The results of these studies, however, are not comparable, because of major differences in study designs.

The discussion on the significance of endocervical cells in the diagnoses of cervical epithelial changes is not closed. Often early repeat smears are recommended when endocervical cells are absent from a smear.

In the Dutch screening programme most Pathology Laboratories recommend to repeat smears

without endocervical cells within one year and to repeat smears without endocervical cells, but with atypia, immediately.

In this study the quality of the cervical smears taken by general practitioners, and also by some practice assistants, in the Dutch Screening Programme in the region of Nijmegen was evaluated. Key questions were:

- What is the percentage of “class 0” smears and cervical smears without endocervical cells for smears taken by the general practitioners and practice assistants?
- Does practical experience/training improve the quality of the smears?
- What sampling devices are used, and what is the quality of the smears for the different devices?

Method

Study population

The study population included all general practitioners in the Regional Health District of Nijmegen who sent preventive smears to the department of Cytopathology of the Academic Hospital St. Radboud in Nijmegen in the first round of the screening (n=136). In this region most GPs, namely 80%, send their smears to this laboratory.

Not included in the analyses were GPs who had started as a GP very recently, retired from practice early in the study period (1989), or those who had taken charge of a practice for a short period. It appeared that they submitted less than 20 preventive cervical smears to the laboratory.

These GPs sent 18,469 preventive cervical smears to this laboratory in the first national screening-round which took place in the period 1989-1992. The invitation of the women in this first round took place in the period 1989-1991, but the smear-taking and analyses by the laboratory took place until february 1992. The study period therefore is january 1989 – february 1992.

The invited women were aged 35 to 54. The hormonal status of the women at the time the smear was taken was known only for 9794 smears: of these 73% premenopausal and 27% postmenopausal.

Of the 18,469 cervical smears these 136 GPs sent to the laboratory, 71 smears were excluded from the analyses because only endometrial cells and no endocervical columnar cells or squamous metaplastic cells were present in the cellular material.

A questionnaire on sampling devices was mailed to the 136 GPs and returned by 111 in the region (82%). The questionnaires of two GPs were returned incomplete and therefore excluded. The analysis including the sampling devices involved therefore 109 GPs.

Data collection

From the records of the department of Cytopathology of the Academic Hospital St. Radboud the following data of the cervical smears were obtained:

- the code of the general practitioner who had taken the smear;
- the date on which the smear was taken;
- the date on which the smear was received by the laboratory;
- “KOPAC”-classification: a descriptive report of the cytological diagnosis of the smear, in which the K-code describes the cellular composition of the smear.¹¹ By means of this coding-system, for the purpose for this study, smears were divided into three categories: “class 0”-smears, smears without endocervical columnar cells (EC-) and smears with endocervical columnar cells (EC+). Cervical smears with squamous metaplastic cells and without endocervical columnar cells were categorized as EC- smears. However, the women from whom these smears were taken need further diagnostic procedures.

For this study “class 0” and smears without endocervical cells were regarded as of insufficient quality. All other smears were regarded as of adequate quality.

To get information on the sample device used, a short questionnaire was mailed to the GPs (February 1993). Questions were asked about:

- the sampling device(s) used;
- whether, and if so when, they had changed sampling device(s).

The data obtained by the questionnaire and the data of the smear could be linked by general practitioner code. Thus screening results could be related to the sampling device used by the GP.

At the start of the National Screening Programme (1989) the laboratory advised GPs to use the cervexbrush. The cervexbrush is a plastic ectocervical brush with flexible “hairs” which follow the contours of the ectocervical surface. The central “hairs” are longer and can reach into the endocervical canal¹².

Results

Of the 18,398 cervical smears, 437 (2%) were diagnosed as “class 0” and 2,907 (16%) smears did not contain endocervical cells (EC-). Of these EC- smears 36 contained squamous metaplastic cells.

The “quality” of the smears per general practitioner varied from 0 to 19.3% for “class 0”, and from 0 to 48.3% for EC-.

Figure 1 shows the frequency distribution of the GPs according to the percentage of smears

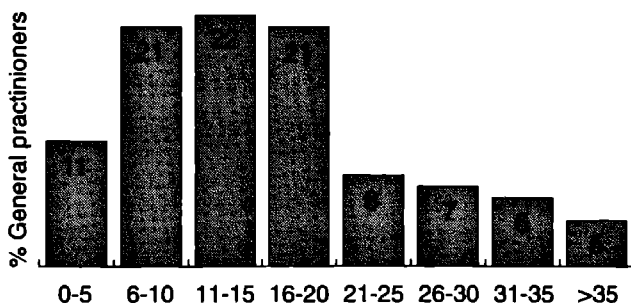


Figure 1. Cellular composition of cervical smears taken bij GPs

without endocervical cells. For 25% of the GPs the percentage of smears without endocervical cells was more than 20. For 46% the percentage EC– smears was more than 15, and for 68% more than 10.

In four general practices in the region cervical smears were taken by the practice assistant (n=6). The percentage of smears without endocervical cells in these practices was 18.

Influence of experience/training

There was no relation between the number of cervical smears sent to the laboratory by the GP and the percentage of smears without endocervical cells (Table 1).

Table 1 *Quality of the smears per number of smears taken by the general practitioner*

Number of smears taken by the GP	No.	"Class 0"-smears			Smears without endocervical cells		
		No.	%	95%CI	No.	%	95%CI
20-100	3081	75	2.4	[1.9;2.9]	479	16	[15;17]
101-150	4044	97	2.4	[1.9;2.9]	575	14	[13;15]
151-200	3058	78	2.6	[2.0;3.2]	499	16	[15;18]
201-250	3830	103	2.7	[2.2;3.2]	672	18	[17;19]
>250	4266	75	1.8	[1.4;2.2]	669	16	[15;17]

Table 2 *Quality of the smears in 1989, 1990, 1991 and 1992 for general practitioners (a) and in 1990, 1991 and 1992 for practice assistants (b)*

Number of smears taken by the GP	No.	“Class 0”-smears			Smears without endocervical cells		
		No.	%	95%CI	No.	%	95%CI
(a) General practitioners							
1989	2080	68	3.3	[2.5;4.1]	399	19	[17;21]
1990	4951	115	2.3	[1.9;2.7]	838	17	[16;18]
1991	3404	66	1.9	[1.4;2.4]	505	15	[14;16]
1992	719	7	1.0	[0.3;1.7]	98	14	[11;16]
(b) Practice assistants							
1990	471	9	1.9	[0.7;3.1]	117	25	[21;29]
1991	369	11	3.0	[1.3;4.7]	48	13	[10;16]
1992	120	0	–		15	13	[7;18]

Table 2 shows the percentage of smears without endocervical cells for 1989, 1990, 1991 and 1992 for all GPs who submitted more than 150 cervical smears to the laboratory. GPs who submitted fewer smears in the study period (3 year and 2 months) were excluded in this analysis, because an 'experience'-effect will be limited for GPs who take on average less than 2,5 smears per week.

During the screening period the percentage of smears without endocervical cells decreased. This difference in percentage is statistically significant for smears taken in 1989 compared with those taken in 1990 and 1991.

Table 2 also shows the percentage of smears without endocervical cells for the six practice assistants for 1990, 1991 and 1992. In 1989 only a few cervical smears were taken by practice assistants. In February 1990 the assistants attended a theoretical and practical course on cervical smear-taking. After this course they had further practical training within their practices. The decrease in the percentage of smears without an endocervical component in 1991 was quite remarkable.

Sampling device

Table 3 shows the sampling devices used by the GPs. As was expected, most GPs used the cervexbrush (93%). Of these 101 GPs, 79 always used the cervexbrush. The remaining 22 GPs sometimes used another device. Most of them indicated that they usually used the cervexbrush and that the use of the cytobrush, cytobrush/cervexbrush combined or cytobrush/spatula combined method was mainly restricted to women who returned for a smear because of a previous smear lacking an endocervical component.

Table 3 *The sampling devices used by GPs*

Sample device	Number of GPs (%)
Cervexbrush only	79 (72%)
Cervexbrush or combination spatula/cytobrush	8 (7%)
Combination cervexbrush/cytobrush	8 (7%)
Combination cervexbrush/cotton swab	2 (2%)
Cytobrush	4 (4%)
Spatula only	2 (2%)
Combination spatula/cytobrush	2 (2%)
Spatula or cervexbrush	4 (4%)
Total	109 (100%)

Table 4 *Quality of the smears per sampling method of the general practitioner*

Sample device	No.	"Class 0"-smears			Smears without endocervical cells		
		No.	%	95%BI	No.	%	95%CI
Cervexbrush only	5321	110	2.1	[1.7;2.5]	774	15	[14;15]
+ sometimes other devices	1335	27	2.0	[1.2;2.8]	169	13	[11;15]
Spatula only	143	10	7.0	[2.8;11.2]	23	16	[10;22]
Combination spatula/cytobrush	106	0	–		10	9	[4;15]
Spatula or cervexbrush	694	17	2.5	[1.3;3.7]	158	23	[20;26]

Table 4 shows the percentage of smears without endocervical cells per sampling device used by the general practitioner. There was no relation between sampling device and the percentage of smears without endocervical cells. But the number of smears taken with other devices than the cervexbrush was small.

A substantial number of GPs (30%) changed their sampling device during the screening. Of the 79 GPs who used the cervexbrush, 13 GPs had first used the wooden spatula and changed to the cervexbrush in the course of 1990. The percentage of smears without endocervical cells decreased within this group of GPs after an increased use of the cervexbrush. Before 1 January 1991 this percentage was 16 (95%CI [11;15]) and after that date 13 (95%CI [14;18]).

Discussion

The validity of the screening-test is important for the effectiveness of a screening programme. Therefore, not only sufficient compliance and adequate follow-up, but also the validity (sensitivity and specificity) of the smear-test is important.

One of the factors influencing the sensitivity, and thereby the false-negative rate, is the cellular composition of the sample.

For this study, the presence of endocervical cells was used as an indicator of the quality of the smear. This is in line with the daily practice of the Dutch screening programme, where a repeat smear is recommended within a year when no endocervical component is present. For this reason, it is important to limit the percentage of smears without endocervical cells. It is important for the cost-effectiveness, the workload of the GPs and the laboratories and especially for the women concerned, since repeated tests can raise anxiety about possible abnormalities.

The sampling device has proved to be important for the quality of the cervical smear. The combination-method of the cytobrush with the wooden spatula appeared to be effective in collecting endocervical and ectocervical cells¹³⁻²⁰. The cervexbrush has also proved very satis-

factory^{12 19 22}. Advantage of the cervexbrush over the combination-method is the simultaneous collection of both endocervical and ectocervical cells with one single device from the area of the transformation zone. Moreover, the cervexbrush is easy to use by inexperienced users^{12 22}. A disadvantage of the cytobrush is a higher proportion of inadequate smears ("class O") due to excessive blood²³.

For these reasons the laboratory promoted the usage of the cervexbrush in our region. Since most GPs (91%) in the region followed this advice, it was not possible to compare the quality of the smears taken with different sampling devices. For the 13 GPs who changed sampling devices during the screening period, the introduction of the cervexbrush showed a slight improvement in the "quality", a decrease of 3% in smears without endocervical cells, of the smears compared with the spatula.

The "quality" of the cervical smears in the region of the study was acceptable; overall the percentage of smears lacking an endocervical component was 16. This percentage varied enormously among the GPs in the region. Of all GPs, 32% had a percentage of smears without endocervical cells in less than 10% of the smears. For one out of four GPs, however, this percentage was higher than 20. Efforts to improve the quality of the smear should be concentrated on individual GPs.

The quality of smears taken by GPs would improve if the general practitioner had more experience in smear-taking.

An option for improvement is more experience of the general practitioner in smear-taking. During the Dutch pilot projects the cervical smears were taken by specially trained paramedical workers. With their practical experience as full-time smear-takers, their percentage of smears without endocervical cells varied from 5 to 10²⁴. As most GPs take less than 100-150 cervical smears per year, they will never get the same practical experience. The results of this study show that the quality of the smears by GPs improved since the start of the national screening programme in 1989. The decrease from 19% in 1989 to 14% in 1992 implies that one out of four women is spared the anxiety caused by a repeat test and it also implies that the cost for repeat smears because of insufficient quality was reduced by 25%.

Another option for improvement of the quality of the cervical smears is extra support by training courses. The remarkable decrease in the percentage of smears without endocervical cells for the practice assistants in 1991 is most likely due to the training-course they followed in 1990. Since the quality of the smears taken by practice assistants after the training course was comparable with that of the GPs in this study population, delegation of taking of the cervical smears to the practice assistant might be feasible.

We recommend offering GPs who do not delegate smear-taking to their practice assistants the opportunity to follow practical training courses in smear-taking. In any case, training in smear-taking should be an important part of the education programmes for GPs.

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CHAPTER 11

DISCUSSION

Wilson and Jungner have defined ten conditions for mass screening programs.¹ Of all cancers, cervical cancer probably fulfils these conditions the best. Cervical cancer has detectable precancerous lesions which are well curable.

There is no doubt that screening programmes for cervical cancer under optimal conditions are effective. The strongest evidence for effectiveness of cervical cancer screening programmes comes from comparisons of time trends in incidence and mortality in populations which introduced mass screening.²⁻⁷ Supportive evidence comes from case control and cohort studies.

In European countries screening programmes were set up in different ways, with varying results. The relation between the extent of organised mass screening and the degree of reduction in mortality and incidence is striking. Figure 1 shows the decline in incidence rates of cervical cancer in the Scandinavian countries.

The first 20 years of cervical screening in the UK have had a limited effect.^{8,9} The main problem with the programmes was the low coverage.^{10,11,12} In an effort to improve organisation of cervical cancer screening in the UK, all health authorities were instructed to introduce a cervical cytology call and recall system in 1988. Since the change in payment to general practitioners for cervical screening in the UK, screening activities increased significantly. The 1990 general practitioner contract sets targets on which payment for cervical screening depends. Payments are triggered on reaching 50% to 80% of the target population. Coverage of the target population between 1989/90 and 1992/93 increased from 61% to 83%.¹³

In summary, the experiences in the Scandinavian countries showed that screening for cervical cancer under optimal conditions can be effective, whereas the first experiences in the UK

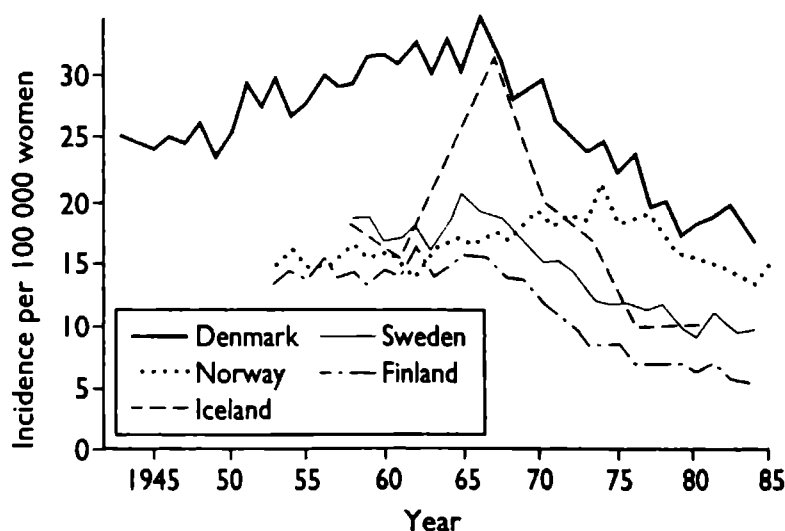


Figure 1. Trends in annual age adjusted incidence rates of invasive carcinoma of cervix in Nordic countries²²

showed that because of barriers, non-optimal conditions can emerge and effectiveness can be limited. Whenever mass screening programs are set up or established programs are evaluated, efforts must be made to reduce barriers for optimal conditions in order to minimize the gap between what is and what can be the effect.

A nationwide screening programme for cervical cancer was started in The Netherlands in 1989. In the programme the women received an invitation by letter from the Local Health Authority to make an appointment with their GP, who takes the smear. Soon after the start of the nationwide screening a number of shortcomings were discovered. These shortcomings mainly concerned the age range of the target population, the call schedule, the call system, the quality assurance, the coordination, the registration, and follow-up.¹⁴ It was concluded that, with the present set-up of the programme, cervical cancer screening can not achieve an optimal effect. Especially, there is concern about the compliance of women with high risk and unnecessary double (opportunistic) screening.

These observations mirrored the concerns that did led to this intervention study: poor compliance and low coverage formed serious barriers for the optimal screening to fulfil its potential: the attendance rates were less than or near 50% in several regions,^{15,16,17,18} and on average about 40%.¹⁴

In this intervention study the participation rates of a general practice-based call system was compared to a control group invited by the national call system (Local Health Authority). The general practice-based call system including a reminder resulted in a 21% higher attendance (Chapter 1,2). The effect of the reminder was 9%.

An important barrier in the national call system is the difficulty of sending reminders. Because the invitor and smear-taker is not the same, monitoring of compliance is a major problem. In the general practice-based call system monitoring of compliance is less complicated. In the intervention study sending reminders was optional. Making reminders a fixed part of the screening programme instead of being an option will increase the effectiveness of the screening programme further.

Defining 'protected' women as those women who attended a screening, had had a smear taken within a year before invitation, or had had a total hysterectomy, the protection rate in the general practice-based call system was 82%. But this figure is probably an underestimation because it was only based on the register of the GP. Furthermore women who had had a recent smear within 3 years before the invitation also can be defined as protected. Figures on this were gathered for a subgroup of 500 women; the 'protection rate' by this latter definition was 91%.

Of course, in the national call system a part of the non-attenders are also not eligible for screening. This percentage depends on screening activities in the past (pilot projects or individual GPs) and differences in the number of hysterectomies, and therefore will differ in the regions.

However, there is no reason to assume that the percentage of women who did not attend a screening and were 'protected' would differ more than marginally between the GP-invited

group and the control group in this study. So, it is concluded that the general practice-based call system achieves a higher participation (compliance) for cervical cancer screening.

Another barrier in cervical screening is the compliance of women with a higher risk for cervical cancer. Frequently, in programmes with low coverage rates the women most at risk are reached the least.

With the general practice-based call system this barrier was reduced compared to the national call system.

The general practice-based call system results in a higher participation rate, particularly in women with elevated risk, compared to a national call system. The sub-study comparing risk profiles showed an 18% higher overall attendance, and a 28% higher attendance of women with greater risk because of sexual behaviour and smoking for the general practice-based call system (Chapter 8).

Overlap between opportunistic screening and systematic screening was the main motive to integrate cervical cancer screening in the general practice. But by delegating the task of inviting women for screening to another instance, the reduction of this overlap, and thereby the increase in the efficiency, is not optimal in this national set-up.

In the general practice-based call system this efficiency is better. GPs are able to exclude women from screening for medical reasons: women who have had a total hysterectomy, had had a recent smear taken, or who are already in follow-up for previous abnormalities. Eighteen percent of the women were thus excluded before inviting for screening each year of the study. This not only reduces the number of unnecessary smears but also needless 'pain' and irritation for the women who have had a hysterectomy.

In addition, GPs who are involved in inviting women for screening will be aware of the call schedule and thereby more likely to take smears within this schedule and take less opportunistic smears. The survey of GPs showed that in the national call system only a few GPs were aware of the actual birth year cohorts invited during a year and none of them were acquainted with the monthly local call schedule (Chapter 5).

Unnecessary double screening can be reduced by a general practice-based call system, but, as opportunistic smears are also taken by midwives and gynaecologists, this might still not be optimal. Improvement of the communication, for instance by standard reporting to the GP of smears taken by someone other than the GP or a central registration of all smears accessible to all smear-takers, can further optimize the reduction of unnecessary smears.

The quality of the follow-up of abnormal smears is also a serious potential barrier. In the national call system it is not clear who is responsible for follow-up. No doubt some if not all responsibility should be taken by the smear-taker, the GP.

The GPs who were involved in the general practice-based call system had on their own initiative set up monitoring systems for follow-up of abnormal smears. Of the other GPs in the region not involved in the project only 50% had set up such a system within the practice. The study showed a 12% higher compliance with follow-up for GPs involved in the general practice-based call system compared to GPs in the national call system (Chapter 9). To a large

extent this effect can be explained by the presence of fail-safe systems in all intervention practices. Involvement of GPs in a GP-based call system had a stimulating effect on the introduction of a fail-safe system within the practices as well as on the responsibility of the GP for adequate follow-up.

Promoting monitoring systems for follow-up to GPs can optimize the quality of follow-up of abnormal smears.

More involvement of GPs in cervical screening leads to greater commitment, which leads to higher efficiency. The greater the commitment of the GP and other practice members the more efforts are made to make the screening a success. The involvement in the intervention study also led to the introduction of the previous mentioned reminder systems and monitoring systems for follow-up of abnormal smears within the practice. And it also led to other improvements in implementing this preventive task within the practice organisation, such as separate sessions for taking smears and delegating the taking of the smears to the practice assistant. This saves time, particularly since it separates the preventive smears from the cure system. The study showed that the quality of smears taken by practice assistants was comparable to that of GPs (Chapter 10).

Because of the previous mentioned shortcomings in the national screening program, the Dutch government has asked the Health Insurance Counsel (Ziekenfondsraad) for advice on improvements.¹⁹ One recommendation urges each region to make a plan for the organisation of cervical cancer screening in association with all actors involved. A number of conditions must be met¹⁹, but the regions have the option of choosing their own professionals to perform the various tasks in the screening programme. A general practice-based call system fits very well in such a regional plan for cervical cancer screening. And the national organisations of GPs, the Dutch College of GPs (NHG) and National GPs Association (LHV), advise the Dutch government to make optimal use of the GP in new preventive tasks in the future. The Dutch College guideline (NHG standard) for cervical cancer screening supports a gradual introduction of the general practice-based call system.²⁰ The system evaluated in this thesis provides an attractive model of organising cervical screening in health regions.

The Nijmegen general practice-based call system for cervical cancer screening has been operational in the region of Nijmegen since 1994. In 1995 the Dutch College of GPs started an implementation programme for program prevention in general practice.²¹ A call system, monitoring compliance and follow-up for cervical cancer screening, is a part of this prevention program.

Another alternative call system for cervical cancer screening was introduced to improve the organisation of cervical cancer screening. With this method, information about the screening programme is mailed to the women by the Local Health Authority. Women who want to participate are asked to return an answer-card, were they also are asked to fill in the name of their GP. GPs receive call-cards from the Local Health Authority for their patients who are willing to participate. This call system is preferable above the original national call system. A disadvantage compared with the general-practice based call system is that the GP has no insight into the women who are not willing to participate – they are not invited by the GP.

The introduction of a general practice based call system depends on the computerisation of practices. Though there is a clear trend towards full computerisation of Dutch general practice, not all practices can be included at this moment. An integrated call system with a regional plan, where GPs who are able to participate can do so, is attractive. Because not all GPs are yet able to participate a coordination centre for matching and support is necessary (Appendix A).

To prevent is better than to cure was and is not always an obviously aphorism for all GPs. But fortunately, in the general practices in The Netherlands, there is increasing attention to preventive medicine – and this study has given such prevention an extra stimulus.

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SUMMARY

In ten general practices a call system for cervical cancer screening was introduced. The attendance rates of a GP-based call system including a reminder, resulted in a 21% higher attendance rate compared to the national call system, where women are invited by the Local Health Authority. The 'protection rate' – the percentage of women who attended, who had had a smear taken up to three years before invitation, or who had had a total hysterectomy – was 91% with the GP-based call system.

The GP-based call system resulted in a higher attendance, particularly in women with elevated risk. A 28% higher attendance of women with greater risk because of sexual behaviour and smoking was achieved by the GP-based call system compared to a national call system.

In the GP-based call system 18% of the women were excluded from screening for medical reasons: women who had had a total hysterectomy, had had a recent smear taken or were already in follow-up for previous abnormalities.

Compared to the GPs in the national call system, a 12% higher compliance with follow-up of abnormal smears was found for GPs involved in the GP-based call system. To a large extent this effect can be explained by the presence of a fail-safe system in all these practices.

The introduction of a call system in the practices led to improvements in implementation of this preventive task within the practice organisation, such as separate sessions for taking smears and delegating the taking of smears to the practice assistant. The quality of smears taken by practice assistants was comparable to that of the GPs; on average 18% of the smears were inadequate. Courses and experience in smear-taking decreased this percentage.

The majority of GPs (91%) in the region were willing to participate in a call system and regional implementation was feasible. A regional GP-based call system was implemented in 36 practices. Conditions for such a regional system are central co-ordination, extra support and stimulating the computerisation of general practices.

Because of shortcomings in the national screening programme, the set-up was reconstructed. Each region now has to make a plan for the organisation of cervical cancer screening in association with all instances involved. These plans must meet a number of conditions, but the delegation of the different tasks in the screening programme are not mandated. A GP-based call system can fit very well in such a regional screening plan.

SAMENVATTING

In tien huisartsenpraktijken is een uitnodigingssysteem van het bevolkingsonderzoek baarmoederhalskanker opgezet.

Het uitnodigen door de eigen huisarts, inclusief een reminder, leidde tot 21% hogere opkomst dan het landelijke oproepsysteem, waarin vrouwen een uitnodiging krijgen van de GGD. De 'beschermingsgraad' – het percentage vrouwen dat opkomt, recent (<3 jr) al een uitstrijk heeft laten maken of geen baarmoeder meer heeft – was bij de huisartsen die zelf uitnodigen 91%.

Het uitnodigen door de eigen huisarts leidde tot een extra verhoging van de opkomst van vrouwen met een hoger risico voor baarmoederhalskanker. Van de vrouwen met een hoger risico (seksuele risicofactoren en roken) was de opkomst 28% hoger bij vrouwen die door de huisarts werden uitgenodigd dan bij het landelijke oproepsysteem.

In de tien huisartsenpraktijken werd 18% van de vrouwen niet uitgenodigd om medische redenen: recent uitstrijk (<1jr), baarmoederextirpatie, of al in follow-up.

Vergeleken met huisartsenpraktijken waarvan de vrouwen via het landelijke systeem werden uitgenodigd was de deelname aan follow-up bij huisartsen die zelf uitnodigen 12% hoger. Grotendeels kan dit verschil verklaard worden uit het feit dat al deze praktijken een bewakingssysteem voor follow-up hebben opgezet in de praktijk.

De invoering van een uitnodigingssysteem in de huisartsenpraktijken leidde ook tot verbeteringen van de implementatie van de cervixscreening in de praktijkvoering. Bijvoorbeeld door het houden van aparte uitstrijkuurtjes en het delegeren van het maken van de uitstrijk naar de praktijk-assistente. De kwaliteit van de uitstrijken gemaakt door assistentes bleek niet onder te doen voor die van de huisartsen, gemiddeld 18% van de uitstrijken was kwalitatief onvoldoende. Door training en ervaring in het maken van uitstrijken daalde dit percentage.

De meerderheid van de huisartsen (91%) in de regio was bereid deel te nemen in een regionaal gecoördineerd huisarts-uitnodigingssysteem, waardoor regionale invoering haalbaar bleek. In 1994 is het uitnodigen door de huisarts ingevoerd in 36 praktijken. Voorwaarde voor zo'n regionale invoering bleken: centrale coördinatie, extra ondersteuning en stimulering van automatisering van de huisartsenpraktijken.

Vanwege tekortkomingen is de landelijk opzet van het bevolkingsonderzoek gewijzigd. Een van de wijzigingen is dat een regionaal samenwerkingsverband een plan moet indienen voor de opzet in de regio. Dit plan moet aan een aantal voorwaarden voldoen, maar het samenwerkingsverband is vrij in de verdeling van verschillende taken. Uitnodiging door de huisartsen voor het bevolkingsonderzoek is goed inpasbaar in zo'n regionaal plan.

APPENDIX

Description of the regional GP-based call system for cervical cancer screening.

The condition for participation in the regional GP-based call system is having a computerised age-sex register within the general practice.

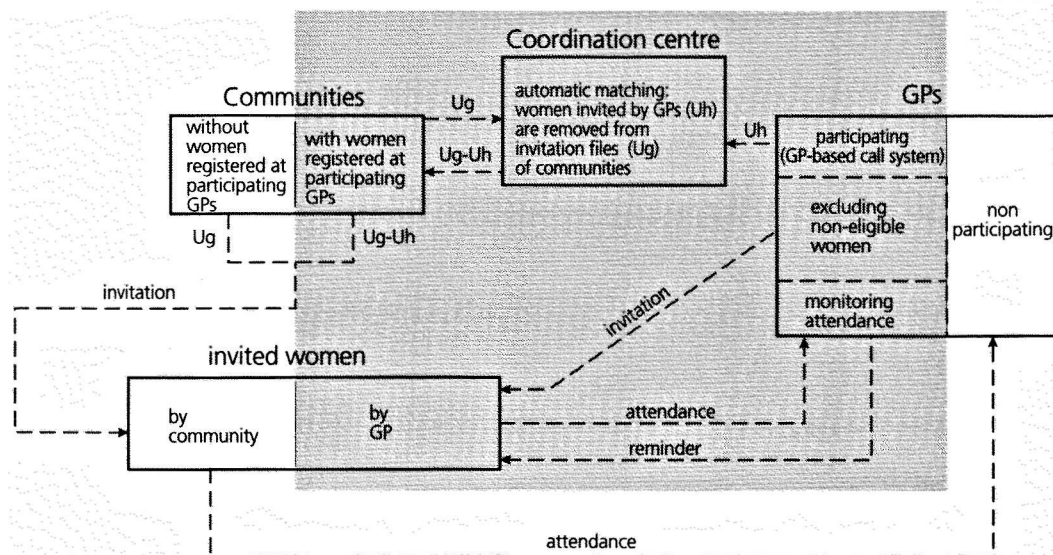
Not all general practices are computerised yet. Additionally, most but not all GPs are willing to participate in a GP-based call system. Therefore, women registered at non-participating practices will be invited by the community/Local Health Authority.

For this reason, at the coordination centre data of women registered with the participating GPs will be matched with the data at the population register. In this way all women are invited and women do not receive double invitations. Moreover, a check is created for incomplete and/or not up-to-date practice registrations.

Invitation scheme – Every year women from certain birth cohorts are invited, following the national call system. In consultation with the involved instances in the regions the invitation scheme is determined. All communities and participating practices receive this scheme and the deadlines for delivering the data, in the beginning of the year.

Appendix A

Scheme of a regional general practice-based call system where not all GPs participate (yet)



Data exchange – Several weeks before the date of invitation the participating practices send the administrative data (on diskette) of the women of the birth cohort that must be invited, to the coordination centre (Uh).

At the same time the communities send the administrative data of the population registers (on diskette) of the specific birth cohort to the coordination centre (Ug).

At the coordination centre these data are matched with a computer program.

Women who will be invited by their GP are excluded from the data file of the population register (Ug-Uh). Next, the 'cleaned' data-file, the file where women invited by the GPs are excluded, are returned to the communities. These women are invited by the communities/ Local Health Authority.

Obviously, for communities where no women are registered with participating practices, matching is not necessary (Ug).

Matching – The computer program matched automatically if the administrative data of a woman of the population register are the same as the data of the practice.

If the data did not correspond totally, the user has to make a decision whether it concerns the same woman.

Administrative imperfections of the practices – with the consequence that a woman might not receive an invitation – are passed on to the concerned practices.

For reasons of privacy, no data from the register of the practices are passed on to the communities.

Invitation – The participating practices exclude women not eligible for screening before invitation. Non eligible women are those who had had a total hysterectomy, had had a recent smear taken (within one year before invitation) or who are already in follow-up for previous abnormal smears.

Communities do not have this information, and therefore invite all women of the returned file.

Participation – All women – those invited by the GP as well as by the community – are invited by letter to make an appointment with their GP to participate in screening. The first group receives this letter from their own GP, the others by the community or Local Health Authority.

Reminder – The participating practices monitor attendance.

Non-attenders receive a reminder.

The communities are not able to monitor attendance. Therefore reminders are not sent.

BIJLAGE

Beschrijving regionaal huisartsen-uitnodigingssysteem voor baarmoederhalskanker.

Minimale vereiste voor deelname aan een regionaal huisarts-uitnodigingssysteem is een geautomatiseerd registratiesysteem in de huisartsenpraktijk.

(Nog) niet alle huisartsenpraktijken beschikken over zo'n geautomatiseerd registratiesysteem. Bovendien zijn de meeste maar niet alle praktijken tot deelname bereid.

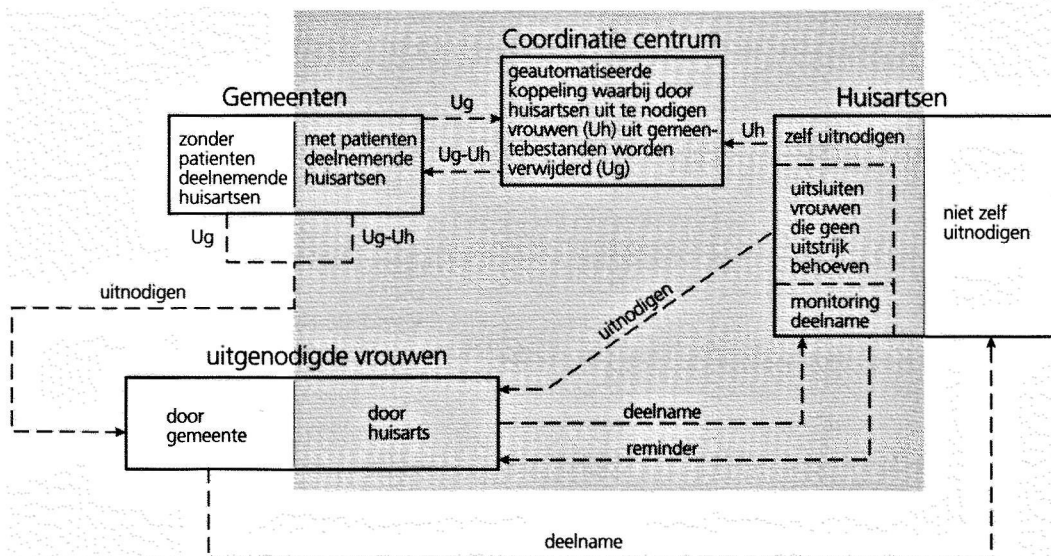
De vrouwen die ingeschreven staan bij deze niet-deelnemende praktijken, zullen dan ook uitgenodigd worden door de gemeente.

Om deze reden vindt op het coördinatiecentrum koppeling plaats van gegevens van de deelnemende praktijken aan die van de gemeenten. Op deze manier krijgen alle vrouwen een uitnodiging en kan voorkomen worden dat vrouwen een dubbele uitnodiging krijgen. Bovendien ontstaat zo een vangnet voor praktijkregistraties die onvolledig of niet up-to-date zijn.

Uitnodigingsschema – Elk jaar worden, volgens landelijk schema, vrouwen uit een aantal geboortecohorten uitgenodigd. In overleg met de betrokken partijen in de regio wordt het uitnodigingsschema van dat jaar vastgesteld. Alle gemeenten en deelnemende huisartsenpraktijken ontvangen aan het begin van het jaar dit schema en de data waarop gegevens ingeleverd moeten zijn.

Appendix A

Model voor een huisartsuitnodigingssysteem in een regio waarbij (nog) niet alle huisartsen deelnemen



Gegevensuitwisseling – Enkele weken voor de uitnodigingsdatum sturen de deelnemende praktijken de administratieve gegevens (per diskette) van de vrouwen van het geboortecohort die op die datum uitgenodigd gaan worden, naar het coördinatiecentrum (Uh).

De gemeenten sturen gelijktijdig de gemeentelijke administratieve gegevens (per diskette) van het betreffende geboortecohort naar het coördinatiecentrum (Ug).

Op het coördinatiecentrum worden deze gegevens automatisch gekoppeld. De vrouwen die door de huisartsen worden uitgenodigd worden uit de gemeentelijke bestanden verwijderd (Ug-Uh). Vervolgens worden de opgeschoonde bestanden naar de betreffende gemeenten teruggestuurd. De vrouwen uit deze bestanden worden door de gemeenten uitgenodigd.

In gemeenten waar geen deelnemende praktijken zijn, kan de koppeling uiteraard achterwege blijven (Ug).

Gegevenskoppeling – Het koppelingsprogramma koppelt automatisch wanneer de gegevens van gemeente en praktijk overeen komen. Bij afwijkingen moet er door bediener een beslissing genomen worden of het om dezelfde vrouw gaat.

Administratieve onvolkomenheden van huisartsenpraktijken – waardoor een uitnodiging zijn bestemming niet of moeilijk zou bereiken – worden aan de desbetreffende praktijken doorgegeven.

Uit privacy-overwegingen worden geen gegevens uit de huisartsregistratie aan de gemeenten doorgegeven.

Uitnodigen – De deelnemende huisartsen schonen voor het uitnodigen de lijst met uit te nodigen vrouwen op. Vrouwen die een totale baarmoederextirpatie hebben ondergaan, in het afgelopen jaar reeds een uitstrijk hebben gehad of reeds in follow-up zijn, krijgen namelijk geen uitnodiging.

De gemeenten beschikken niet over deze gegevens en nodigen alle door hen uit te nodigen vrouwen uit.

Deelname – Alle vrouwen, zowel zij die door de gemeenten als zij die door de eigen huisarts zijn uitgenodigd, worden verzocht een afspraak met hun eigen huisarts te maken voor deelname. In het eerste geval worden de vrouwen door de GGD of gemeente hiertoe uitgenodigd, in het tweede geval door hun eigen huisarts.

Reminder – De deelnemende huisartsen houden bij welke vrouwen wel en welke vrouwen geen gehoor geven aan de uitnodiging (monitoring). Aan de non-responders wordt een reminder gestuurd.

De gemeenten beschikken niet over deze opkomstgegevens en verzorgen dan ook geen reminder.

DANKWOORD

Voor de uitvoering van het onderzoek, het schrijven van de wetenschappelijke publicaties en het proefschrift willen we allen die hieraan hebben bijgedragen bedanken voor hun steun, inzet, hulp, advies en medewerking.

Omdat het velen waren, kunnen we niet iedereen persoonlijk bedanken. Alle medewerkers van de onderzoeks-praktijken en betrokken gemeenten willen we bedanken voor hun deelname. Zonder hun medewerking en met name ook de inzet van de praktijk-assistenten was ons project niet mogelijk geweest.

Dank ook voor de ondersteuning door vele van onze voormalige collega's van de afdeling Huisartsgeneeskunde van de Katholieke Universiteit van Nijmegen. Op vele gebieden konden we op jullie steun rekenen.

Dank ook aan de begeleidingscommissie van ons project.

Onze welgemeende dank ook voor de promotoren, Chris van Weel en Peter Vooijs en de copromotor Wil van den Bosch. Naast de intensieve, maar vooral ook stimulerende en positieve begeleiding van het onderzoeksproject, willen we jullie met name bedanken voor het vertrouwen dat jullie altijd in ons hadden.

Zeer speciaal danken willen wij ook Erny Wentink. Zij begon als onderzoeksassistente van ons project, maar groeide uit tot 'manager' van het oproepsysteem en werd de steun en toeverlaat van ons en de deelnemende praktijken. Ook na ons vertrek runde zij nog geruime tijd het project. Zonder Erny hadden wij het project en proefschrift nooit kunnen afronden. Dank daarvoor, maar vooral ook voor de prettige samenwerking tussen ons drieën.

Herman Beekers danken wij voor de vormgeving. Maar daarnaast willen we hem, Marc, en onze kinderen Wouter, Daan, Thomas, Anna en Lisa, bedanken dat jullie er zijn.

CURRICULA VITAE

Ineke Palm werd geboren op 9 maart 1951 in de gemeente Bergh. In 1969 behaalde zij het diploma HBS-B aan het Ludgercollege te Doetinchem. Aansluitend studeerde zij drie jaar Geneeskunde aan de Katholieke Universiteit te Nijmegen.

Na een roerige en productieve loopbaan in bedrijfsleven, politiek en huwelijk begon zij in 1985 aan een nieuwe studie aan dezelfde universiteit, ditmaal in de Gezondheidswetenschappen. Als afstudeerrichting koos zij epidemiologie, met als afstudeerstage een onderzoek van 5 maanden naar de risicofactoren naar moedervlekken, een pilot-studie voor een onderzoek naar risicofactoren voor melanoom. Na het behalen van het doctoraalexamen in 1989 was zij enkele maanden wetenschappelijk docente bij dezelfde sectie Epidemiologie.

In september 1989 werd zij aangesteld als wetenschappelijk onderzoeker aan de afdeling Huisartsgeneeskunde van de Katholieke Universiteit van Nijmegen. In die functie (1989-1994) voerde zij samen met Agnes Kant het onderzoeksproject uit dat leidde tot onderliggend proefschrift.

In 1994 heeft Ineke Palm de Universiteit verlaten om beleidsmedewerker te worden van de Tweede-Kamerfractie van de Socialistische Partij. Een functie die zij tot op heden vervult.

Agnes Kant werd op 20 januari 1967 te Hessisch-Oldendorf in Duitsland geboren. In 1985 behaalde zij het VWO-diploma aan het Stedelijk Lyceum te Zutphen. Aansluitend begon zij aan de studie Gezondheidswetenschappen aan de Katholieke Universiteit te Nijmegen. Als afstudeerrichting koos zij epidemiologie, met als afstudeerstage een onderzoek van 5 maanden naar de risicofactoren naar moedervlekken, een pilot-studie voor een onderzoek naar risicofactoren voor melanoom. Dit onderzoek voerde zij uit samen met Ineke Palm, en tijdens deze stage werd de basis gelegd voor hun verdere samenwerking.

Na het behalen van het doctoraalexamen in 1989 werkte zij gedurende 3 maanden op de afdeling psychiatrie van het Academisch Medisch Centrum te Amsterdam. Gedurende deze periode schreef zij een onderzoeksplan en -programma voor een op te richten instituut voor verslavingszorg.

Aansluitend op deze functie werd zij aangesteld als wetenschappelijk onderzoeker aan de afdeling Huisartsgeneeskunde van de Katholieke Universiteit van Nijmegen. In die functie (1989-1994) is het onderzoeksproject uitgevoerd van onderliggend proefschrift.

In 1994 heeft zij de Universiteit verlaten om beleidsmedewerker te worden van de Tweede-Kamerfractie van de Socialistische Partij. Een functie die zij tot op heden vervult.

