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Cervical cancer screening in The Netherlands

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Abstract

The Netherlands is among the European countries with low incidence and almost lowest mortality from cancer of the uterine cervix. Screening started around 1970, being a combination of local and regional invitational programmes and opportunistic screening. In 1996 screening activities have been structured to a new national and nationwide programme. The restructuring concerned the management and financing of the programme, organisation, target age-ranges and interval, follow-up of abnormal test results, and evaluation. At the moment short-term results of implementation of the new screening programme are becoming available. It will take many more years before long-term effects of the new programme will emerge. © 2000 Elsevier Science Ltd. All rights reserved.

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1. Introduction: epidemiology and screening history

In Europe, The Netherlands is among the countries with low incidence (8.1 new cases per 100 000 women annually in 1994, European standardised rate [ESR]) and almost the lowest mortality from cancer of the uterine cervix (2.5 per 100 000 women annually in 1994, ESR). The number of cancer cases of the 'uterus, not otherwise specified' is very low. Mortality stabilised between 1950 and 1965. Between 1965 and 1970 mortality started to decrease. This decrease occurred before an effect from screening could be expected. The decrease continued after the introduction of screening, and currently the mortality rate is lower than 40% of that obtained around 1960. An approximate indirect estimate is that half of the decrease in mortality is due to screening.

Since the introduction of cervical cancer screening in The Netherlands around 1970, there has been a combination of local and regional invitational programmes and opportunistic screening. Since 1996, there has been a national cervical cancer screening programme, covering

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the whole country. However, opportunistic screening still occurs. The total number of smears in 1996 was 1 000 000, of which 450 000 were smears taken in an organised programme, 300 000 other primary smears and 250 000 secondary (follow-up) smears (repeat smears after smears without endocervical cells and other inadequate smears, repeat smears after 'borderline' results and follow-up smears in referred and treated women).

2. Population and methods of the screening programme

The current national screening programme is coordinated by the Dutch Health Insurance Council, which, on behalf of the government, bears the responsibility for quality control and financing. The organisation is largely decentralised, leaving the actual running of the programme to nine regional screening centres. It is ensured that all professionals involved (including general practitioners (GPs), pathologists and gynaecologists) are represented in these regional centres.

Since 1996, the age range of the target population was extended from 35–53 to 30–60 years of age, and the interval following a negative result from 3 to 5 years, leaving the number of seven invitations a lifetime unchanged. The programme is financed by the government.

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The target population on a national level consists of 3.6 million women, one-fifth of which is eligible annually. The programme is population-based and the cohorts invited (by the Local Health Authority, municipality or general practitioners) are fixed by year of birth. It covers all municipalities of the country. The names and addresses of the eligible women are obtained from the population registries. In a growing number of cases, GPs are involved in the call and recall process (a minority of whom issues the (re-)invitations themselves), and in these cases women who had a recent (within a year) smear or a total hysterectomy are temporarily or definitively excluded from invitation. Involvement of GPs in the invitation system proved to be more effective, with a higher attendance and coverage, than invitations by an authority, and a nationwide prevention programme runs to enhance the role of the GPs in the cervical screening (Prevent: maatwerk). Women are invited to make an appointment with their GP (in The Netherlands every individual in principal is linked to a GP of his own choice) to have a Papanicolaou (Pap) smear. Sometimes alternative instances to have the smear are also offered. Most of the programme smears are taken in general practice, by GPs or their practice assistants. In the future, probably the delegation of taking smears to the practice assistants will increase, because a lot of courses for practice assistants are now being organised. Programme smears are free of charge.

Smears are taken with a cervical brush or wooden Ayres spatula sometimes combined with an endocervical brush. Which one is used depends on the laboratory the smear taker is working with, since the laboratory provides the devices for smear taking. The screening procedure does not include gynaecological examination.

There are approximately 70 pathology laboratories in the country, of which nearly all read screening Pap smears (programme and/or opportunistic). The number of smears read annually varies widely per laboratory, approximately 5000 to more than 50000. The screening is performed by specially trained cytotechnicians, by a head cytotechnician (evaluating the non-negative cases sorted out by the cytotechnicians) and by cytopathologists (who evaluate and write the final report on the non-negative cases sorted out by the head-cytotechnician). For a full time cytotechnician, a maximum of 5500 programme smears per year is set by the quality assurance guidelines of the laboratories [1]. Smears that can not be evaluated because of inadequacy must be repeated six weeks after the inadequate smear. Negative smears without endocervical cells must be repeated after 6 months. The costs for both types of repeat smears are free of charge. Borderline smears (atypical squamous cells of undetermined significance (ASCUS) plus minor dysplasia) must be repeated after 6 months. Smears with moderate dysplasia or higher-grade abnormalities must

be followed-up by the gynaecologist with colposcopy, during which biopsies are often taken. Since there is no nationwide or regional colposcopy registry, the number of colposcopies per year per colposcopist is not known. Repeat smears after borderline smears, and follow-up and treatment procedures at the gynaecology department are not free of charge. In the screening programme in 1996, 1% of the smears could not be evaluated because of inadequacy, 8% of the smears were negative, but lacked endocervical cells, 6% had borderline abnormalities (this previously was 10% in The Netherlands) and 0.5% contained at least moderate dysplasia. Altogether, 84% of the smears were negative and adequate. In 1997, the frequency of borderline smears had decreased to 4% and of negative adequate smears had increased to 87%.

Usually, an attending woman has to wait 2 weeks for her smear result. In some regions, written notifications are sent both to the GP and to the women, in other regions only the GP is informed and usually the women are asked to contact their GP for the smear result. In any case, the GP is responsible for the woman being informed of her smear result and for the follow-up to be completed. Once a woman is referred, she comes under the care of her gynaecologist, who keeps the GP informed of her diagnosis and management. Laboratories are planning to provide GPs with lists of incomplete follow-up, as a helpful device to minimise the number of women with inadequate follow-up.

2.1. Quality assurance

For quality control and evaluation on a national level, data of different sources are used. Since 1990, all 70 pathology laboratories in The Netherlands have been linked with the PALGA (Dutch Network and National Database for Pathology). This means that information about all cytological and pathological investigations performed in these laboratories is registered in this national datafile. With this network, laboratories can check possible activities in other laboratories, although this requires additional communication (the system only displays the fact that cytology or pathology in other laboratories is performed for persons with the same identification code, without specifying the type of examination or the result). For the identification of the patients, the date of birth, the four first digits of the name at birth and the gender are entered. This identification is not 100% unique, and evaluation tables have to be adjusted. PALGA until now has been the main provider of data used for evaluation. The regional screening centres are providing data about the number of eligible, invited and attending women. The number of attending women comes from the laboratories which inform the screening centres. This is done on an individual

level to enable recalling the non-attenders. Currently, there are no data available from the gynaecology departments. On the one hand, the consequences of this omission are limited, because the diagnoses can be traced by the cytological and histological specimens that are produced by the gynaecologist and evaluated in the laboratories, the result of which is recorded in the PALGA. On the other hand, information about colposcopies and destructive therapies (mainly cryotherapy) is not available. Incidence and mortality are registered on a national level by the cancer registration and the CBS (Central Bureau of Statistics), respectively. These registries are not yet linked to screening registries.

Guidelines concerning cervical cancer screening have been issued by the Dutch Health Insurance Council (national guidelines concerning the screening programme) [2] and the respective professions. This includes quality assurance, professional qualification and accreditation. Quality assurance guidelines have been issued by general practitioners [3], the pathologists [1] and the gynaecologists [4], separately. However, a recent evaluation study proved that the quality of the chain of the whole process of succeeding activities for the cervical cancer screening should be checked. Therefore, the set-up of a quality assurance system (including the guidelines of the different professionals) has been advised.

Whether advertising campaigns, by any means, are issued and which information folders are used is decided upon at a regional and local level. There is a 'national' folder to inform the women who are invited to attend the programme which is used by part of the regional screening organisations.

A first national report concerning 1996 and 1997 (the initial years of the new programme) on the quality and outcome measures is in preparation. The coverage of screening activities (programme plus opportunistic) is approximately 80% (percentage of women of 30–64 years of age that had at least one smear in the previous 5 years at the end of 1996). It is too early to estimate the effectiveness of the new programme.

3. Conclusion

The cervical cancer screening activities in The Netherlands have been structured to a new national and nationwide programme which was started in 1996. This restructuring concerned the management and financing of the programme, organisation, target age ranges and interval, follow-up of abnormal test results, and the evaluation. It will take at least 5 years before the changes result in a new more or less steady situation in the process of the programme. Long-term effects will take many more years to emerge. The national evaluation report on the first 2 years (1996 and 1997) of the restructured programme is in preparation, and will allow for conclusions on the short term results of the implementation of the new screening programme.

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