# **Editorial**

# Cervical screening in Hungary: why does the "English model" work but the "Hungarian model" does not?

A. Kovács<sup>1</sup>, M.D.; L. Döbrőssy<sup>1</sup>, M.D., Ph.D.; A. Budai<sup>1</sup>, I. Boncz<sup>2</sup>, M.D.; Á. Cornides<sup>3</sup>

<sup>2</sup>Department of Health Economics, Policy and Management, University of Pécs <sup>3</sup>Regional Institute of National Public Health and Medical Officers's Service, Budapest (Hungary)

#### **Summary**

A comparison has been made between the English practice and the "Hungarian model" of cervical screening. In England, until 1986, extensive opportunistic screening was the practice, but – as it had no effect on cervical cancer mortality – afterwards, the screening policy was changed to be strictly in line with international recommendations. On the other hand, in Hungary, the "old practice" has been petrified: gynaecologists are the "gatekeepers", a "gynaecological examination completed with smear-taking for cytology" makes up the screening strategy. Although in the frame of a National Public Health Programme all the prerequisites for nation-wide organised screening have been provided, and an up-to-date screening strategy declared, 20-times as many smears are taken and analysed outside as inside the programme, and the efforts have had no impact on cervical cancer mortality. This is because "old habits die hard". There is an urgent need to reconsider the screening strategy, and to reorganise the cervical screening practice in Hungary.

Key words: Opportunistic and organised screening for cervical cancer; Role of gynaecologists; Impact on mortality from cervical cancer.

#### Introduction

Cervical screening, as a public health policy, has proved its effectiveness in terms of reduction of mortality from the target disease in the target population [1] and today its wide application is strongly recommended by international bodies, such as the International Agency for Research on Cancer of the World Health Organization (IARC/WHO), the International Union against Cancer (UICC), and the European Council [2, 3]. Hungary (a Central-Eastern European country, one of the former "Eastern block" countries which joined the European Union in 2004) has made tremendous efforts to develop a nationwide cervical screening programme; however, the difficulties faced in this endeavour are also tremendous. This is because the country has to carry the burden of the past. It may therefore be worthwhile to develop an understanding of the history of cervical screening in Hungary, so that others can avoid the same problems.

## History of screening in Hungary

Non-organised or opportunistic cervical screening has a long history in Hungary: it goes back to the late 1950s, and has gone through three phases.

First phase: colposcopy vs cytology

The first phase was characterised by choosing the proper screening tool. Originally, the screening tool was *colposcopy alone*, applied by oncologists engaged in practicing oncological-gynaecology. In 1954, a ministerial decree (MOH 8834/31/1954) was issued which described the mode of operation of the National Oncological Institute and that of the country-wide network of the some 70 oncological care units (consisting of one physician "specialist in oncology", and one nurse in each, geographically covering the whole country, a unique but ineffective formation in the countries of the "socialistic system". It stated that "mass screening must be conducted in such a way that each woman over 30 years of age must be screened by colposcopy". There are no data on effect.

In the mid 1960s cytology as a screening tool had emerged in the developed countries, and in Hungary "colposcopy completed by cytology" had become the screening test. More and more cytology laboratories – based on pathology departments – had been established, and by early 1970, the entire country was fully covered. In 1972, a "School of Cytotechnology" to provide regular training for pre-screeners (5 days a week for 10 months) was established, and the

system of "pre-screening" introduced. The training has continued, and today some 300 fulltime "pre-screeners" are at work. By the end of the 1970s, there was sufficient capacity to carry out three yearly screening for all eligible women: the existing system is in place to meet the demands of mass screening [4, 5].

Second phase: oncologists vs gynaecologists

Screening to begin with was carried out almost exclusively by a limited number of oncologists who were unable to meet the workload demands. In 1978, a joint deliberation/statement was issued by the Board of Gynaecology, saying, firstly that "every gynaecological examination should be preformed as a screening", in other words, screening had to be considered as an integral part of the gynaecological examination, and that there should be "no cervical screening without cytology" [6]. In practice, smears were taken by gynaecologists as part of a "complex gynaecological examination, including colposcopy" and then, they were analysed in cytology laboratories by pre-screener cytotechnologists, supervised by cytopathologists and finally, reported back to gynaecologists, who – depending on the results – managed the patient. As a result, the gynaecological community had become highly involved. During the 1980s, a country-wide "cervical screening programme" was declared, and extensive opportunistic screening, including a smear-taking tool had taken place [7]. The annual number of smears analysed exceeded one million. The clinical stages of the detected cervical abnormalities had shifted favourably, but the mortality from cervical cancer had not decreased, but did level off at a rather high level (10 per 100,000 population). It was admitted officially that the program had failed [8].

The reason for the failure was perceived to be the *lack of individual identification and registration*. Only the number of smears examined, and not the women screened had been registered. No one knew who had been screened. Certain women – a self-selected group within the target population (approximately 30% of the eligible population) – had been screened unnecessarily frequently, several times a year, while other women had never been screened.

## Third phase: clinical practice vs public health measure

In the mid 1990s, as part of the World Bank-sponsored "close the gap" programme, a secondary prevention sub-component was carried out which covered three primary cancer sites: i.e., screening for cervix, breast, and colorectal cancer, the three sites where scientifically sound evidence of effectiveness is available. The establishment of a National Cancer Registry was part of the exercise [9]. The implementation of a "secondary prevention" sub-component has created a favourable policy-environment for integration of organised population screening as a core function of the health care system, thus a golden opportunity was presented to reorganise and update cervical screening in Hungary. However, at this point in time, the question presented itself as to whether what was called "screening" was a widespread clinical exercise, or a routine public health policy and programme. In the view of the gynaecological community, it seemed to be the former one. In opposition to their standpoint, the public health authority argued for a "state-of-the-art" screening strategy, and held the "English model" up as an example, where to a large extent, and from a historical perspective at the beginning, the situation was comparable to the Hungarian one.

## The "English model"

Transition from opportunistic to organised screening

It is a matter of common knowledge today that, in England, the National Health Services (NHS) operates a very effective mass screening programme for cervical cancer [10]. Cervical screening began in the 1960s undertaken by enthusiastic cytologists. By the 1980s many programmes had developed at a local level, but on an *ad hoc* basis. Over four million smears were analysed each year. However, it was clear that cervical screening was not as effective or well managed as it could be with clear objectives, particularly due to the lack of a national call/recall system to identify and invite eligible women. Some women at greater risk of developing cervical cancer were not screened and some who were screened were not followed up appropriately [11].

The current national system was introduced in 1987. The Department of Health required each health authority in England to establish a computerised call and recall system. It also emphasised the need to introduce good local management and to nominate an individual to be responsible for the organisational effectiveness of cervical screening in each district. The NHS Cervical Screening Programme (NHSCSP) was established to bring together the health departments, professional bodies and designated members to facilitate the adoption of common standards and working practices throughout the United Kingdom.

## Organisation of screening

The NHS is the provider of screening; it is funded by general taxation, and free at the point of delivery. Ninety-eight percent of the population is registered with the NHS. The NHS owns the hospitals and employs the doctors who work in the hospitals. The general practitioners are self-employed contractors to the NHS. Primary Care Trusts (PCTs) are groups of general practitioners who cover a certain geographical area. A woman needs to be registered with her general

practitioner to become a beneficiary of the system. The Department of Health gives the money to PCTs in proportion to their population. The PCTs "buy" health services from hospitals, including screening services, for their population.

In each region, screening departments have been set up from where the overall programme managing these departments are responsible for holding and updating the database of the women who are eligible for cervical screening. The source of the notification list for screening is the "Exeter System", made up from general practitioners' lists, which contain the personal details of everyone who is registered with the NHS. The name and address of all women eligible for screening is taken from this database which also identifies their general practitioner. The invitation letters are issued by the screening services; however, the primary care personnel play a key role, as they check the completeness and accuracy of the notification lists. Women aged 25-64 years of age are eligible for cervical screening. The screening interval is three to five years according to age. The "non responder cards" are sent to the woman's general practitioner in the confident expectation that the general practitioner will take an interest in these non-responders and try to encourage them to have a smear test. If no result is received, the woman will remain in the programme and further invitations will be sent at the appropriate interval.

# Smear taking and follow-up

Most importantly, the smears are taken in the primary care setting, sometimes by general practitioners but more usually by practice nurses, and sent to the local cytology laboratory, where the smears are registered, processed and analysed. The primary care team is fully advised on the guidelines to be followed and how to take cervical smears. As for the follow-up, an appropriate "failsafe" procedure has been established: the smear takers must assume full responsibility for seeing the result and ensuring that appropriate action is taken, including follow-up for non-attendance. When a positive result is received from the laboratory, they are to initiate follow-up action, i.e., referral to colposcopy for an appropriate gynaecological opinion. Colposcopy clinics are integral to the operation of the programme. Quality standards for colposcopy clinics are set by the national programme although gynaecologists are expected to use their own judgement. Results and management plans are communicated to the referring general practitioner.

## Quality Assurance System

Quality assurance is a fundamental part of the NHS Screening Programme. To this effect, a country-wide system has been developed and implemented. The aim of quality assurance is to maintain minimum standards, and encourage continuous improvement in the performance of all aspects of screening to ensure that women have access to high quality screening services wherever they live.

#### Results

On 10 August, 2006, 79.5% of eligible women aged 25-64, residents of England, had been screened at least once in the previous five years, and resulted in an adequate test result. In 194 out of 303 Primary Care Organisations the coverage was 80% or higher. In 2005-2006, about 4.06 million women were invited for screening, and 3.6 million women were screened by the NHS Cancer Screening Programme. The laboratories examined just under 4 million smears, including early recalls for surveillance (14%), following findings of abnormalities (4%), and inadequate smears (6%). Ninety-two percent of the total were submitted by general practitioners. For women referred to a colposcopy clinic following persistent non-negative smears, 0.1% were found to have invasive, and 0.5% showed in situ cervical cancer (CIN3).

The NHS Cervical Screening programme is remarkably successful. The age-standardised incidence was reduced proportionally to the coverage of the program [12], and, the mortality from cervical cancer decreases by 7% a year; it has already saved a large number of lives and will continue to prevent about 4.500 deaths every year in England [13].

## The "Hungarian model"

## Organisation of the screening

As a result of the "model programmes" which were carried out on a limited scale, and following a thorough evaluation, a proposal was submitted to the government to introduce evidence-based organised screening as a routine service into the health care system in Hungary. The proposal was well received, and since 2000 three screening modalities – cervical screening among them - have been included in a National Public Health Programme [14]. The responsibility for implementation, coordination, monitoring quality control and evaluation of the screening programmes has been delegated by law to the Chief Medical Officer's (CMO) office. This office – as a public health authority - is in charge of a countrywide network of medical officers, having an institution in each of 19 counties and the capital, charged with the responsibility for public health issues, population screening being included. In the CMO's office, a Screening Coordination Department has been established, which supervises the Screening Coordinating Units in the 20 administrative areas. Most importantly, a National Screening Registry has been set up, and receives a population list from the database of the Health Insurance Fund Administration (OEP), comprising personal identification data of virtually the entire

Hungarian population. The list is broken down by county, and sent out to the primary care physicians who are able to validate it for use as a notification list.

## The screening strategy

There has been a heated debate with the gynaecological community, which has revolved around three issues: (a) what constitutes a screening test, (b) the age-range during which screening should take place, and (c) the interval between screenings. The Board of Gynaecologists argued in favour of the traditional "gynaecological screening", meaning a complete gynaecological examination with full colposcopy, and smear-taking for cytology. The physical examination of breasts is also included in the gynaecological protocol [15]. In the Board's view, screening should start at 18 years of age, or whenever regular sexual activity commences, it should never be discontinued, and should take place once a year. This obviously contradicts the international recommendations of population screening, and there have been calls for reorganisation and updating of existing screening strategies (2). A compromise agreement has been reached on the target age-range and the interval between two consecutive screenings, but not on the method of screening. Accordingly, the screening strategy states that: "after one negative smear, once in every three years, full gynaecological examination comprising both colposcopy and cytology, of women between 25 and 64 years of age". This means that the gynaecologists remain the "gatekeepers" of population screening.

## The screening process

The personal invitation to women between 25 and 65 is centrally issued by a letter, informing the invitee about screening, and what the expected benefits and risks are ("informed decision"). It encourages women to see a gynae-cologist, either a private one or one of those listed in an annex to the invitation letter. Conventional smears are taken by a gynaecologist as part of a "complex gynaecological examination, including full coloscopy". The smears are sent to a cytology laboratory where they are processed and analysed. Cytology is not centralised: some 80 laboratories applied for financing, and some 50 have been accepted. At the end, the test-result is sent back to the gynaecologist who informs the patient. Screening is free for women. The National Screening Registry receives the screening result from the screening units in an aggregate form, because – by the data protection laws – dealing with any information on an individual's health-related status is strictly forbidden.

## The current status of cervical screening in Hungary

The experiences of the first few years of operation are disappointing. Between 2004 and 2006, about 2 million invitation letters were sent out, and fewer than 96.000 women, 5% of those invited, attended for screening. This compliance rate is totally unacceptable! In the meantime, in 2005 alone, the National Health Insurance Fund Administration paid for 960,000 smears taken from 850,000 women as "gynaecological diagnostic cytology" (OENO code 29 601), and only for 40,520 smears originating from screening (OENO code 42 700). The difference is shocking, and requires an explanation, whether the former number really covers "diagnostic gynaecological examinations", or screening cytology is being reported under a diagnostic financal code. Most likely, the latter is true. Presumably, more women "get moving" under the influence of an the invitation letter, than reflected in the data of the Screening Registry.

## Reasons for low compliance

The difficulties in the transition from an extensive opportunistic screening to an organised screening are being reflected in the current problems of population screening.

Traditionally, the "gatekeepers" of opportunistic screening were the gynaecologists, and this has become fixed in the mind of the general public. As a result, without waiting for an invitation letter, or receiving but ignoring one, means smear-taking is done on the occasion of any gynaecologist-patient encounter, disregarding the existence of the organised screening system – it is reported to the financing agency as a "diagnostic exam", and not as a screening exam. These cases are not registered by the Screening Registry because the cytology laboratories are obliged to report only those smears that turn up with the perforated slip of the invitation letter. Furthermore, only those cytology laboratories contracted by the National Health Insurance Fund Administration for funding are obliged to report. As a consequence, the gynaecologists working in private clinics do not report the activity even though they are estimated to screen about 30% of eligible women. Similarly the cytology labs do not report the work either.

A further reason for the low compliance is that access to "screening facilities" – meaning gynaecologists – is limited. According to the list given by the Board of Gynaecologists, there are "879 workplaces suitable for screening", however their geographical distribution is rather heterogeneous: gynaecological services are easily accessible in big cities, their number is less in small towns and in the countryside they are virtually non-existent. It is "uncomfortable" for country women to travel to towns for screening. Mobile services would be likely to alleviate this problem.

The outstanding role the primary care physicians could play in mobilising women to accept the screening offered is totally under-utilized. A "target payment" system – similar to that in England – to encourage them to take a greater part is under consideration; scarcity of resources is a major obstacle in this respect.

#### Discussion

There are similarities and differences in the development and operation of cervical screening programmes in England and Hungary. In both countries, screening started as an extensive non-organised, opportunistic smear-taking activity, which had reached high numbers of cervical smears analysed, but the population targeted was not adequately covered. Therefore, the programme missed those at high risk. As a result, the intensity of screening did not result in the decrease of incidence and mortality. In England, it was realised much sooner that they were on the wrong track, the old practice was discontinued, and an organised cervical screening programme was developed according to the up-to-date international recommendations, adapted to local needs. Good results followed and years later the mortality from cervical cancer started to significantly decrease.

The case of Hungary is different. The fact that we are on the wrong track was realised much later, and was not addressed appropriately. Instead of discontinuing ineffective practice, they have reached a compromise solution. The result is shameful: unacceptably low compliance, and no epidemiological impact on cervical cancer rates.

What could make cervical screening work in Hungary? By now, major progress to develop a country-wide organised cervical screening system capable of regular screening of all eligible women has been made. The management and information system, and the cytological capacity are in place. However, our hands are totally bound by the traditional mode of screening: the insistence of the gynaecological community on their "historical role" seems to be the major impediment to carry out an effective screening programme. There have been attempts to break through. In some selected areas of the country, properly trained midwives and primary care nurses – temporarily, under the supervision of local gynaecologists – are taking the smears. In case of non-negative cytology, full-scale gynaecological examination follows, colposcopy included. The results of the "model" are encouraging; however, there is a long way to go until a "state-of-the-art" cervical screening programme – such as in England – could be delivered in Hungary, because "old habits die hard".

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Address reprint requests to: L. DÖBRŐSSY H-2181 Iklad, Parti út 33 Budapest (Hungary) e-mail: dobrossy@freemail.hu