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Cervical cancer screening in Belgium

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Abstract

A description is given of the burden of cervical cancer and the status of screening in Belgium until 1998. Screening is essentially opportunistic and generally performed at yearly intervals. A programme for organised screening — promoting one cervical smear every 3 years for women aged between 25 and 64 years — is being set up in the Flemish Region alone. Important progress has been made concerning the development of technical guidelines on the collection of an adequate Papanicolaou (Pap) smear, uniform terminology for the cytological report and the follow-up of positive tests. The implementation of the programme is confined to the provinces that are instructed to make women and physicians aware of the screening policy. The establishment of a screening register, allowing for individualised invitation of women, was hampered by strict privacy laws and by the heterogeneity of software used for data entry in cytological laboratories. The impact of the Flemish programme was further limited since the reimbursement of smear taking by a gynaecologist or a general practitioner (GP) and the cytological reading are not conditioned by the respect of guidelines. This is due to the fact that the organisation of preventive healthcare and the financing of medical activities concerns distinct authorities. The coverage of the target population is good in Flanders (82.3% according to certain estimates), but is achieved at the expense of an important amount of over-screening. The coverage is lower in the Walloon and the Capital Region. Rationalisation of the policy regarding cancer screening involving all concerned authorities of the country is necessary.

Keywords: Cervical cancer; Cytological screening; Organisation of screening; Belgium

1. Introduction

An overview is given of the burden of cervical cancer and the organisation of screening in Belgium. In order to understand the important differences between the south and the north, it is useful to introduce briefly the federal structure of the country. This article deals mainly with the Flemish situation at the end of 1998. Less information is available on the two other regions.

1.1. Politico-administrative structure of Belgium

Belgium has a very complex political structure. It is divided into three geographically separated regions: the Flemish Region (female population of 3.0 million), the Walloon Region (1.7 million women) and the Capital Region of Brussels (0.5 million women) (see Fig. 1). Another administrative layer, based on linguistic criteria, is superimposed on this: the Flemish, the French and the German community. The Capital of Brussels belongs to both the Flemish and French communities. The heterogeneous repartition of administrative responsibilities complicates decision-making in sectors such as social affairs and public health.

The organisation of preventive healthcare in Belgium is, since the state reform in 1980, confined to the communities, while curative care remains a national matter. A formal cervical cancer screening programme, based on the European guidelines, currently exists only in the Flemish community. It is not applied in the Brussels Region.

1.2. History of cervical cancer screening

Periodical screening by specialised mobile teams or in fixed centres has been organised since 1965. This vertical system was abandoned in the beginning of the 1980s because of low attendance. Meanwhile, opportunistic screening, by private gynaecologists and to a lesser degree by general practitioners (GPs), has gradually increased.

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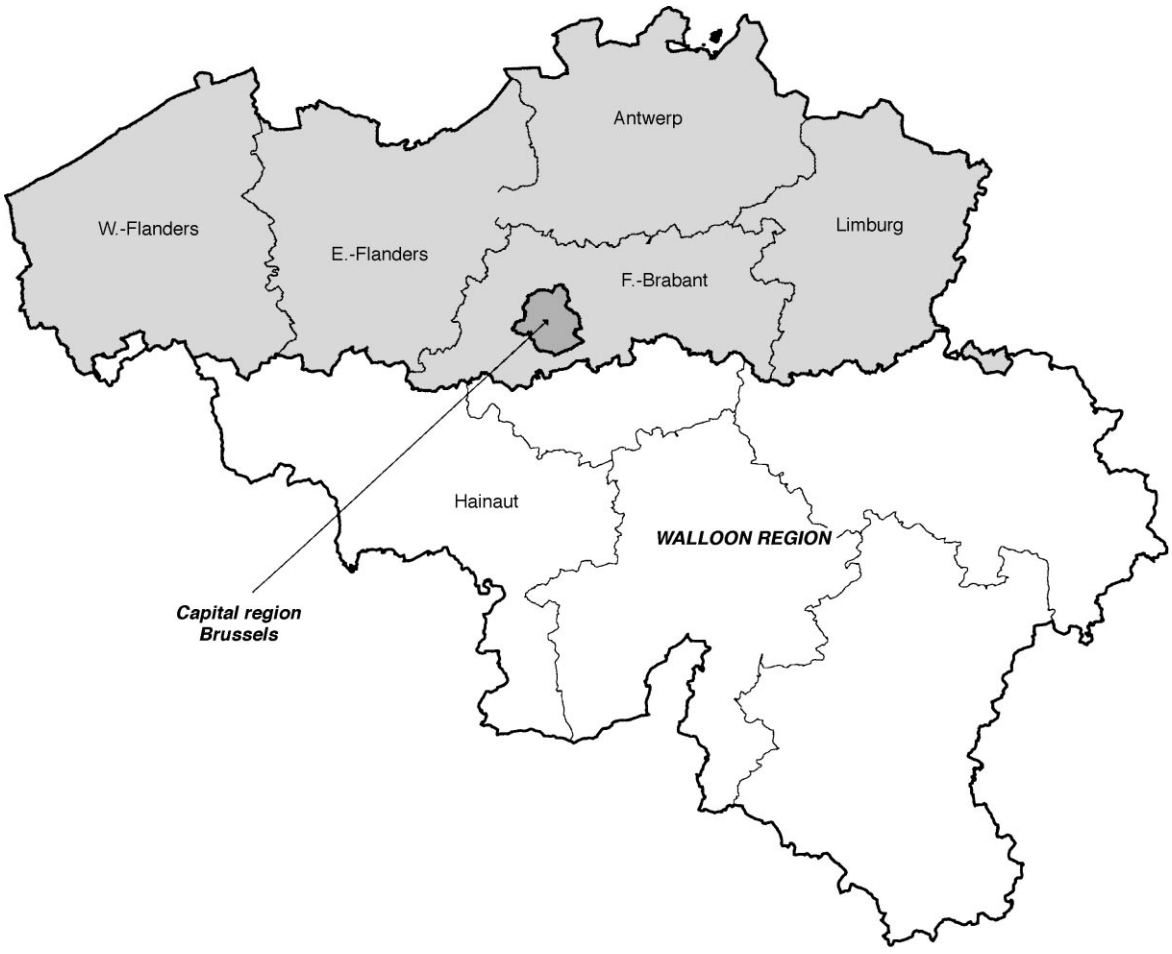

Fig. 1. Belgium is divided into three regions. Currently a cervical screening programme exists only in the Flemish Region. It is implemented at a provincial level.

In 1994, the Flemish Government decided to re-orientate the organisation of secondary prevention of cervical cancer according to the European guidelines [1]. Since then, early detection of cervical cancer is evolving from strictly opportunistic to more organised screening.

2. Incidence and mortality

2.1. Incidence

In 1993, the National Cancer Register (NCR) reported 749 cases of cervical cancer of which 482 (64%) cases occurred in the Flemish Region, 206 (28%) in the Walloon Region and 61 (8%) in Brussels. The crude rate is 14.5 cases per 100 000 women-years for the whole of Belgium. The annual age-standardised rate, based on the world reference population, is $10.8/10^5$ women. Cervical cancer ranks third after breast and colon cancer. The cumulative incidence between 0 and 74 years is 1.02%. The incidence trend is difficult to study using the figures published by the NCR since 1943, because of the poor quality of cancer registration in the past. Even the most recent figures should be interpreted with caution, because of the existence of two important sources of bias: under-declaration of new invasive cases and inconsistent inclusion of carcinomas *in situ*. The net result is probably an overestimation of the real incidence. The extrapolation from the estimated mortality, calculated by Black and colleagues, in 1997 [2], provides certainly a more realistic estimation of the age-standardised incidence: $7.6/10^5$/year.

2.2. Mortality

Mortality due to cervical cancer is not exactly known because of certification problems in relation to the cause of death due to uterine cancer. In 1993, 477 women died of cervical cancer or unspecified uterine cancer: 220 (46%) in Flanders, 208 (44%) in the Walloon Region and 47 (10%) in Brussels. For 2 cases the location at death was unknown. Of these deaths, 46.7% were certainly attributable to cervical cancer. This proportion varied significantly by region: 57.7%, 36.5% and 42.6%

in the Flemish, Walloon and Brussels Region, respectively. The annual crude mortality rate due to certified cervical cancer, expressed by 100 000 women was: 4.33 for the whole of Belgium, 4.30 in the Flemish Region, 4.47 in the Walloon Region and 4.00 in Brussels.

The mortality rate of cervical cancer has declined slowly (slope of $-0.7/10^5$/year) in the last three decades. This trend becomes more important after correction for the death certification bias ($-2.8/10^5$/year). The decline in the death rate was not uniform over birth cohorts. An important decrease was observed for women, born between 1920 and 1935. For younger cohorts, a more stable or even a rising trend was apparent, indicating an increased risk of cervical cancer. A more detailed description of mortality trends in Belgium was presented by Vyslouzilova and colleagues in 1997 [3].

3. The Flemish cervical cancer screening programme

3.1. Aims

The general principles, formulated in the European *Guidelines on Quality Assurance in Cervical Cancer Screening* [1] form the basis of the Flemish programme. It targets almost 1.6 million women between 25 and 64 years old, residing in the Flemish Region. Nine and a half per cent (9.5%, 95% confidence interval: CI 8.9–11.3) of the Flemish female population in the age group 25–64 years underwent a total hysterectomy [7]. This proportion should be subtracted from the total population. Women belonging to the target population are advised to have a cervical smear taken every 3 years by their general practitioner or a gynaecologist. The aimed coverage is 85%. Special effort has to be made to reach women, who are currently under-screened, while opportunistic over-screening should be discouraged. This objective should be achieved by individual invitation to women who have not been screened recently (i.e. <3 years ago). A population-based screening register will therefore be created. Systematic approach and central management of prevention files by general practitioners is another complementary strategy, which should lead to further optimisation of the coverage.

3.2. Involved partners and responsibilities

The five Flemish provinces are responsible for the implementation of the programme in the field. A special co-ordination unit was created at the Scientific Institute of Public Health in Brussels.

Working groups, gathering experts from different disciplines, were created in order to study technical questions and formulate guidelines. The 'Working party for the Uniformisation of Cervical Cytology (WUCC)' has elaborated a standard reporting protocol for the Papanicolaou smear, inspired by the Bethesda system. The WUCC has to formulate instructions for quality assurance in cytopathological laboratories. Recommendations for the further management of cytological lesions were specified by the 'Follow-up working group'. Another working group is developing instructions on sampling techniques to obtain satisfactory smears.

Until recently, several technical advisory commissions dealing with specific health problems advised the Minister of Health. The *Flemish Advisory Board for the Prevention of Cancer*, for instance, was responsible for primary and secondary prevention of cancer. Currently, new structures concerning health prevention are being set up by the Flemish government. In 1997, the *Flemish Health Council* was created, which will in future assist the minister in the development of health policy. The *Health District* (in Dutch: *LOGO*) will be responsible for the local co-ordination of the implementation of prevention activities. This *LOGO* will be managed by a public health officer and a social worker and will cover a population of 200 000–300 000 inhabitants. It will constitute a forum of collaboration and deliberation for all partners involved in primary healthcare. Meanwhile, the provinces are still carrying out the current screening programme. It is not yet clarified how and when the new institutions will take over.

3.3. Medical personnel

The Flemish cervical cancer screening programme is integrated in the routine curative care system. Although GPs share an increasing part of cervical cancer screening, most Pap smears are still taken by gynaecologists. Sixty-nine per cent (69.0%, 95% CI: 66.2–71.6) of women between 25 and 64 years of age, included in a cross-sectional survey, declared their last smear was taken by a gynaecologist, while only 30.4% (95% CI: 27.7–33.1) were taken by a GP [4]. These proportions are not expected to change significantly in the future among the screened women as approximately one-third (95% CI: 31.3–37.2%) stated they would contact a general physician for their next smear. Women, who are currently not covered (generally from older age groups and lower socio-economic categories), are more likely to accept the proposition of a GP taking the smear. A Flemish consensus has been achieved among the professional groups involved concerning the necessity to inform each woman's GP of the dates and results of Pap smears taken by a gynaecologist. Structural measures are needed to translate this recommendation into practice.

In the Flemish Region, more than 100 laboratories exist for pathology or clinical biology, where cervical smears are processed. From a total of 620 000 smears, interpreted in Flanders in 1993, 8.9% were read by gynaecologists.

For the execution of campaigns, one part-time co-ordinator is appointed in each province. He/she is

assisted by an administrative team and a steering committee, composed of representatives of the concerned professional groups and of the provincial administration.

3.4. Creation of a screening register

A central screening register, linked to population files and with the national cancer register, is being set up for the whole Flemish Region. Its main objectives are: (1) targeted invitation of women who need another smear (*call–recall*); (2) monitoring of epidemiological indicators for the evaluation of the screening programme; (3) epidemiological research; (4) recuperation of screen-positive women, who escaped from follow-up (*fail-safe*); (5) feedback to collaborating cytological laboratories and clinicians; (6) study of the occurrence of interval cancers by linkage with cancer registration. All these objectives can be achieved by the implementation of a unique identification method. The privacy of the women should be guaranteed by encryption of the identifying data and the inclusion of an external population bank, where the decryption key is kept for the conversion of ID codes into nominative data allowing call–recall. The medical databank, located in the Scientific Institute of Public Health, will contain complete anonymous screening histories. The Flemish Government has to decide on the designation of the population bank soon, the scenario of data flow and the financing of the registration system. The Commission for Privacy Protection will judge on the judicial aspects. In the past, the registration of medical personal data was conditional upon obtaining the written consent of the concerned informed individual. Nevertheless, the National Board of Physicians, requested to give advice on the 'double-track' transmission procedure (applied in Flemish-Brabant see below), stated the system was not in contradiction of the principle of medical confidentiality, which every physician has to respect.

Hopefully, a legal basis for a population-based computerised registration and invitation system will be established in due course. The adaptation of the restrictive Belgian privacy law, according to European directives, might create an opening.

3.5. Technical guidelines, sampling, cytological interpretation and follow-up

3.5.1. Uniform cytological reporting of cervical smears

A cervical smear should be interpreted according to the Flemish reporting system, elaborated by the WUCC working group and based on the Bethesda System. A data entry software programme has recently been developed, allowing cytological laboratories to follow this WUCC standard. All important cytological services will be visited in the near future in order to install this data entry package or to extract and convert data, stocked in a specific structure, to the standard format. Procedures are being worked out for future data transmission to progressively build up the Flemish cytological screening register.

3.5.2. Follow-up advice

Advice for further follow-up, based on the judgement of specimen adequacy and the possible suspect cytological aspects of squamous or glandular epithelial cells, constitutes an integral part of the Pap smear report. The normal screening scheme (every 3 years) is proposed if a satisfactory smear is interpreted as normal or shows only benign changes with the exception of hyperkeratosis or absence of endocervical cells. In the latter cases, a repeat Pap smear test will be suggested after one year. A repeat smear after 3–6 months is recommended for the following cases: unsatisfactory smear, atypical squamous cells of undetermined significance (ASCUS), low-grade squamous intra-epithelial lesion (SIL), atypical glandular cells of undetermined significance (AGUS) (endocervical origin or unclear origin). When epithelial cells can not be categorised because of infection or atrophy, a repeat smear within 3–6 months after antimicrobial or hormonal treatment can be suggested. Direct reference to a gynaecologist for further investigation is indicated if there is: repetition low-grade SIL, ASCUS, AGUS (endocervical or unknown origin); AGUS (endometrial origin); high-grade SIL or suspicion of cancer; abnormal presence of endometrial cells in postmenopausal women not under substitution therapy. This advice is always explicitly accompanied by the formula "if clinically indicated". The clinician is responsible for further management of the patient taking into account the cytological report, the complete clinical context and the possible follow-up compliance.

3.5.3. Sampling

Illustrated guidelines are being prepared on adequate sampling of representative cells of the transformation zone, adjacent to the squamous and cylindrical epithelium.

3.6. The experiences of the Flemish provinces

Three of the provinces (Limburg, West and East Flanders) organise campaigns by sending out invitation letters to all women in the target age groups. By this invitation, women are encouraged to have a Pap smear taken by their general practitioner or gynaecologist, if they have not already been screened less than 3 years ago. By a short questionnaire, women are asked about their current screening status and their intention to have a smear in the near future. Information, collected this way, has only limited evaluative value, as it is conditional upon the willingness of women to fill in and send back the response forms. In Antwerp, a selective call–recall system was tested in accordance with the law on

privacy protection. Women were requested for their signed consent to register the date and the result of their smears, which would be the basis for future invitations. The proportion of women, who accepted to sign this document, was low (for instance < 10% in some municipalities around Mechelen). Antwerp demonstrated that adherence to a call–recall system conditioned upon the individual written authorisation is condemned to fail. In Flemish-Brabant, another, more complex, registration and invitation system was set up. A double track data flow was conceived emanating from the cytological laboratory. Identifying data (ID) with the preparation number (PN) are sent to a population bank, where IDs are matched with the national register numbers (NR), which are encrypted into an ID code (NR′). ID codes and unencrypted PNs are sent consecutively to the central cytological register. Medical data (MD), certain demographic information and PNs are transmitted directly from the Laboratory to the cytological register, where they can be linked uniquely, via the PN, with the anonymous ID codes (NR′) received from the population bank. At appropriate moments the ID codes (NR′) from recently screened women can be selected and transmitted to the population bank for re-conversion to readable NRs. These can be subtracted from the total target population yielding a file of women to be invited. An address file is then sent to the provincial co-ordinator responsible for the invitation. Some of the main results of analysis of the registers of Antwerp and Flemish-Brabant are presented in Tables 1 and 2.

3.7. Attendance rate

The attendance rate, defined as the proportion of women in the target population with a recent Pap smear (< 3 years ago), was measured by a telephone interview among a sample of 1500 women residing in the Flemish Region and attainable by telephone [5]. The rate was estimated as 82.3% (95% CI: 80.1–84.4) for all women between 25 and 64 years of age and 85.2% (95% CI: 82.9–87.1) when hysterectomised women were excluded. The screening status increased sharply up to 25 years of age and remained higher than 85% up to 40 years of age; from then on it decreased progressively. Socio-economically deprived groups and single women were less likely to have a smear taken. Important regional differences existed. The screening coverage was significantly lower in the province of West Flanders. Over-screening (interval less than 3 years) was the rule, especially among younger age groups. The prevalence of risk factors (sexual intercourse at young age, multiple sexual partners, contraceptive pill use, smoking) has increased over the time, but women at higher risk were generally not screened less than the general population.

In 1997 a health interview survey, including some questions on cervical cancer screening, was organised, in the three Belgian Regions [6]. The attendance rate in the Flemish Region, using the same definition over the same age categories, was 8.9% lower (95% CI: 5.5–12.3) than estimated by the telephone survey.

3.8. Quality assurance

Formal guidelines on quality assurance of all processes in the cytological laboratory do not yet exist, but are one of the future priorities. Targeted reviewing of negative smears of women at risk (previous cervical abnormality or clinical suspicion) is a generally applied method to diminish the risk of false-negative results. Positive slides, detected by a cytologist, are routinely transferred to the pathologist for confirmation in order to maximise specificity. Currently, a European research project is being carried out in six Flemish and one German laboratory. The diagnostic performance of four quality control methods (rapid reviewing, complete reviewing, computer-assisted reading and automated screening) will be investigated in a controlled trial.

Quality judgement of specimen adequacy is an essential part of the cytological report of the Pap smear sent to the clinician who has taken the smear. Periodical feedback is foreseen on individual scores of sample takers compared with the general distribution of scores throughout the region.

3.9. Cost of cervical cancer screening

Approximately 400 000 screening smears are needed annually to cover 85% of the target population of the

Table 1
Distribution of the quality judgement of cervical smears (screening registers of Flemish-Brabant and Antwerp, 1996–1998)

Province	Flemish-Brabant (n = 100 966) (%)	Antwerp (n = 25 122) (%)
Optimal	60 646 (60.4)	17 803 (71.2)
Sub-optimal	39 158 (39.0)	6957 (27.8)
Inadequate	602 (0.6)	250 (1.0)
Missing values	560	118

Table 2
Prevalence of squamous cytological lesions detected in cervical smears (screening registers of Flemish-Brabant and Antwerp, 1996–1998)

Province	Flemish-Brabant (n = 100 339) (%)	Antwerp (n = 24 871) (%)
Normal	90 562 (97.4)	23 780 (95.8)
ASCUS	1259 (1.4)	608 (2.5)
Low-grade SIL	678 (0.7)	298 (1.2)
High-grade SIL and cancer	435 (0.5)	149 (0.5)
Missing values	7405	36

ASCUS, atypical squamous cells of undetermined significance; SIL, squamous intra-epithelial lesion.

Flemish Region, while currently probably 650 000–700 000 Pap tests are taken. Unfortunately, there are no precise readily available figures from the National Health Insurance Institute (NHII) at the regional level. The estimated current budget for the medical activities relating to cervical cancer screening in Flanders, supported by the NHII is approximately €17 million. It has been estimated that the stringent application of organised screening at a 3-year interval could result in a yearly saving of €4–5 million for the health authorities [7].

There is also an important over-consumption for colposcopy. In Belgium, one colposcopic examination is done for every three smears.

3.10. Data collection systems

Information on mortality and incidence is provided respectively by the National Institute of Statistics and by the National Cancer Register (see above). The latest published national figures date from 1993 for mortality and 1992 for incidence. (Note: the National Cancer Register data for 1993, mentioned above, are not yet published; they were directly obtained from the Register.) For the Flemish Region, the data of 1997 are already available.

No reliable systematic data collection system has been set up to monitor the screening status. The NHII provides only absolute figures on the total number of medical procedures in Belgium. Individual physician- or institution-related profiles are produced, but without any differentiation of patient characteristics. This latter type of material can only be provided by the seven *Health Care Insurance Funds*, currently existing in Belgium. Group-specific coverage or participation rates can theoretically be calculated from sickness funds data files, but this is rarely carried out. Table 3 shows the total number of Pap smears taken in Belgium and the number of women between 25 and 64 years old. The ratio between the two figures can be considered as an approximate quantity, somehow related to the screening status [1]. The prevalence and incidence of cervical lesions detected by screening can be estimated from the existing screening registers. A linkage between the Flemish cytological screening register and the cancer register will allow identification of interval cancers in the future. All data dealing with cervical cancer or Pap smear screening are collected and analysed at the Flemish co-ordination unit at the Scientific Institute of Public Health.

Table 3
Ratio of the number of smears taken per year in Belgium and ratio of the number of smearsdivided by the number of women aged between 25 and 64 years old (National Health Insurance Institute)

Year	*n* of smears	Ratio	Year	*n* of smears	Ratio
1983	418 518	0.17	1991	1 063 566	0.40
1984	607 206	0.24	1992	1 122 220	0.42
1985	635 692	0.25	1993	1 117 918	0.42
1986	746 718	0.29	1994	1 140 258	0.43
1987	823 915	0.32	1995	1 125 443	0.42
1988	899 947	0.34	1996	1 190 868	0.44
1989	941 887	0.36	1997	1 158 280	0.43
1990	1 063 701	0.40			

4. Situation in the south of Belgium

In 1992, a broad consensus on cervical cancer screening was accepted by the cancer detection centres of the French-speaking universities and confirmed by the concerned professional scientific societies [18]. The European guidelines and the Flemish instructions on uniform cytological interpretation and follow-up are generally agreed upon. The definition of the target age group is somewhat different. It is proposed that Pap smear screening should begin 3 years after initiation of sexual contact. Despite the scientific support, no formal screening programme is organised in the French community. The estimated proportion of women aged 25–64 years, who have been screened less than 3 years ago is respectively 64.0% (95% CI: 60.9–67.1) and 64.1% (CI: 60.7–67.5) according to the Health Interview Survey (HIS) in the Walloon Region and in Brussels [6]. Some recent telephone surveys in the province of Hainaut show significantly higher results than the corresponding HIS study [9–11].

Taking a smear in the Walloon Region, more than in Flanders, is considered the task of the gynaecologist. Only 17% of the Walloon GPs versus 73% of their Flemish colleagues, participating in a Belgian study in 1995 on cancer prevention, declared that they took Pap smears themselves [12].

5. Discussion and conclusions

Opportunistic screening is still dominant in all Regions of Belgium. In Flanders, an organised screening programme according to the European recommendations is being established. Nevertheless, the evolution to a more organised approach is slow, as it depends upon the voluntary adaptation of professional behaviour of physicians, which is not always evident in a liberally organised healthcare system. A relatively high coverage rate of the target population has already been achieved, but at the expense of an important degree of over-screening. Two urgent decisions need to be taken by the Flemish Health Minister: the creation of an administrative legal frame for a screening register and the re-installation of structural deliberation among the partners involved.

Estimations of the screening coverage differ according to the type of data collection. In the future, more reliable

estimation tools or validated study methods are needed. Despite these methodological discrepancies, it can be stated that the participation in the south is significantly lower than in the north of Belgium. Policy makers in the French community should be convinced to set up projects equivalent to those operating in Flanders.

Straightforward implementation of cancer screening programmes is hampered by the fact that the financing of screening is governed by the national authority, while its organisation is regulated at the community level. Further rationalisation of screening should increase the means available to be invested in the optimisation of the participation rate and quality assurance. Differentiated remuneration systems should motivate care-providers to inform women correctly, to make non-covered women aware of screening and to obtain adequate specimens of the cervix at the indicated intervals. General practitioners should play a more important role, since they are often in contact with patients from lower socio-economic categories, who are generally women that undergo less screening.

Accurate cytological interpretation of the smears in certified laboratories, assuring high quality of reading, clear communication with the sample takers and regular transmission of data to the central register will also require special funding. The required financial resources could be found by re-investing the funds released by the reduction of over-screening [6]. Therefore, communication between the different political levels that make these decisions is needed. The development of a European policy in this matter could facilitate and accelerate this process

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