European Journal of Cancer (2015) **51**, 950–968

Available at www.sciencedirect.com

ScienceDirect

journal homepage: www.ejcancer.com

Original Research

Cervical cancer screening in Europe: Quality assurance and organisation of programmes

K. Miriam Elfström [a], Lisen Arnheim-Dahlström [a], Lawrence von Karsa [b], Joakim Dillner [a,c,*]

[a] *Department of Medical Epidemiology and Biostatistics, Karolinska Institutet, Box 281, 171 77 Stockholm, Sweden*
[b] *Quality Assurance Group, Early Detection and Prevention Section, International Agency for Research on Cancer, 150 Cours Albert Thomas, 69372 Lyon CEDEX 08, France*
[c] *Department of Laboratory Medicine, Karolinska Institutet, 141 83 Stockholm, Sweden*

Received 23 December 2014; received in revised form 5 March 2015; accepted 9 March 2015
Available online 25 March 2015

KEYWORDS
Cervical cancer screening
Prevention
Quality assurance
Guidelines
Health policy

Abstract ***Background:*** Cervical screening programmes have reduced cervical cancer incidence and mortality but the level of success is highly variable between countries. Organisation of programmes is essential for equity and cost-effectiveness. However, there are differences in effectiveness, also among organised programmes. In order to identify the key organisational components that determine effectiveness, we performed a Europe-wide survey on the current status of organisation and organised quality assurance (QA) measures in cervical cancer prevention programmes, as well as organisation-associated costs.
Methods: A comprehensive questionnaire was developed through systematic review of literature and existing guidelines. The survey was sent to programme organisers, Ministries of Health and experts in 34 European Union (EU) and European Free Trade Agreement (EFTA) countries. Detailed aspects of programme organisation, quality assurance, monitoring, evaluation and corresponding line-item costs were recorded. Documentation of programme guidelines, protocols and publications was requested.
Results: Twenty-nine of 34 countries responded. The results showed that organised efforts for QA, monitoring and evaluation were carried out to a differing extent and were not standardised, making it difficult to compare the cost-effectiveness of organisation and QA strategies. Most countries found it hard to estimate the costs associated with launching and operating the organised programme.

* *Corresponding author at:* Department of Medical Epidemiology and Biostatistics, Karolinska Institutet, Box 281, 171 77 Stockholm, Sweden. Tel.: +46 7688 71126; fax: +46 8 314975.
E-mail address: joakim.dillner@ki.se (J. Dillner).

http://dx.doi.org/10.1016/j.ejca.2015.03.008

Conclusions: To our knowledge, this is the first questionnaire to request detailed information on the actual organisation and QA of programmes. The results of this survey can be used as a basis for further development of standardised guidelines on organisation and QA of cervical cancer screening programmes in Europe.

1. Introduction

Cervical cancer screening efforts are underway to varying degrees in most European countries. Evidence from countries where organised screening was implemented early, shows significant decreases in cervical cancer mortality [1]. Also, evidence from England, Finland, Italy and the Netherlands demonstrate decreases in incidence and mortality following implementation of organised screening [2–4]. Organised cervical screening has been shown to reduce cervical cancer mortality by up to 80% at the population level with the level of mortality reduction related to the screening programme coverage [1]. The International Agency for Research on Cancer (IARC) and the 2008 European guidelines for quality assurance in cervical cancer screening recommend that screening programmes should be organised and population-based with a defined target population and screening interval (including organised quality assurance at all levels and organised monitoring and evaluation of programme effectiveness over time) [5,6]. In contrast to opportunistic testing, organised screening programmes can achieve greater equity in screening access and more efficient use of healthcare resources by ensuring that all individuals at risk are targeted within the most appropriate time-frame.

An estimated 54,000 women are diagnosed with cervical cancer and 25,000 women die from the disease each year in Europe [7]. Country-specific age-standardised incidence rates of cervical cancer vary across the European region from 2.1 to 23.9 per 100,000 women per year [7] and mortality rates range from 1.1 to 13.7 [8]. This variation begs further investigation into the current status of screening programme organisation and associated quality assurance efforts.

The first guidelines for quality assurance in cervical cancer screening in Europe were published in 1993 and outlined principles of organising screening, monitoring its impact and ensuring quality of the screening test [9]. A recommendation of the Council of the European Union in 2003 established implementation of screening programmes for the prevention of cancer as a priority for member-states [10]. The updated European guidelines for quality assurance in cervical cancer screening from 2008 were expanded to reflect advances in screening technologies and prevention strategies [6]. Definitions of key performance indicators, as well as recommendations for register-based programme audits using data on cervical cancer cases and controls were also included. Previous evaluations of the status of screening programme implementation in Europe and the quality assurance within programmes have focused on examining efforts in individual countries and monitoring key indicators outlined in the guidelines [11–14]. Results of these studies have highlighted the differences in programmes between countries and need for more systematic evaluation of how programmes are organised and what quality assurance activities are possible in different countries.

The overall aim of the study was to identify the key components of organisation and evaluation of preventive policies without which the potential health gains of cervical screening would be more difficult to attain, and to estimate the funding required. To further support on-going and emerging cervical cancer prevention efforts, a broader analysis of the organisation and quality assurance activities as well as the associated costs of organisation and QA was conducted. The specific aims were to identify which quality control indices are used by the screening programmes in European countries, to evaluate how the measurement of key components of those quality control indices relate to the cervical cancer protection achieved, to propose guidelines on how to define and measure the quality indices that are most effective for cervical cancer control, and to estimate the financial resources required to monitor them. Establishing a baseline description of how cervical cancer screening is implemented in European countries with regard to organisation and quality assurance is important for being able to evaluate efforts to optimise programmes.

2. Methods

2.1. Survey development and structure

A comprehensive questionnaire was developed through an extensive review of the literature and the current European guidelines and protocols. Four out of seven sections of the questionnaire were dedicated to collecting information about cervical cancer screening efforts. The remaining three sections addressed human papillomavirus (HPV) vaccination programme efforts and are the subject of a separate report [15]. In the cervical cancer screening sections, information on (i) screening programme organisation, infrastructure and

operational costs, (ii) screening programme quality control and effectiveness, (iii) screening programme monitoring system and (iv) cervical cancer audits was requested. The items in the survey were designed as a mix of short-answer and open-ended questions. Copies of standard operating procedures, annual reports and other publications were also requested to provide further evidence of programme activities and document the programme dissemination strategies. The EU recommends organised, population-based screening programmes with quality assurance at all levels [6]. This survey was designed to capture the extent to which screening, as currently undertaken in Europe, is in agreement with these recommendations.

The questionnaire was first sent to screening programmes in three of the countries known to have programmes with high cancer-protective effect (Norway, Sweden and England) and to the Screening Quality Assurance Group at the International Agency for Research on Cancer for comment. The piloting was intended to improve completeness and readability of the survey. Comments were integrated into the questionnaire and the text was adjusted accordingly. A copy of the survey is included as supplementary material.

2.2. Data collection

The survey was sent to ministries of health, key screening programme administrators and/or researchers associated to the programmes in all 34 European Union (including separate surveys sent to England, Northern Ireland, Scotland and Wales) and European Free Trade Agreement (EU/EFTA) countries. No country or programme was excluded in the request for participation. In case of non-response, the surveys were resent and the list with possible contacts of administrators or researchers extended. Using a snowball sampling technique, if the first contact could not respond to all sections of the survey, additional experts were requested and surveys sent to these contacts for the collection of further details. Countries were encouraged to work collectively on a survey response since the information requested was both detailed and comprehensive. Furthermore, countries were requested to respond with information on the current status of their programmes to reflect actual programme operations and were asked to provide data on regional level variations if programme organisation differed across the country. The oldest available cervical cancer incidence estimates were collected from IARC's Cancer Incidence in Five Continents (available from http://ci5.iarc.fr/CI5i-ix/ci5i-ix.htm) and current estimates were obtained from GLOBOCAN 2012 (available at http://globocan.iarc.fr/Pages/online.aspx) or IARC's Cancer Incidence in Five Continents. These estimates were obtained to show crude estimates of incidence change over time for European countries (and are included in Table 1). Data collection commenced in May 2012 and concluded in March 2014 (the first response was received on June 7th 2012 and the last response was received on March 21st 2014).

2.3. Data analysis and definitions

Survey responses were reviewed and entered manually into a database. If ministry of health and other responses conflicted, both results were recorded and discrepancies discussed among the authors. We decided that conflicting evidence should be presented and described as such. Correspondence from the survey respondents containing additional information and supplementary documentation submitted with the survey responses were saved and evaluated with the survey responses. The results were presented in tabular form. Terms used in the questionnaire and the analyses were defined according to the 2008 EU guidelines, unless otherwise noted. Publicly mandated programmes have a law, official regulation, decision, directive or recommendation that provides the public mandate to implement the programme with an authorised screening test, examination interval, target group and funding and co-payment determined. Organised programmes provide for a national or regional team responsible for implementation and require providers to follow guidelines, rules, or standard operating procedures. They also define a quality assurance structure and mandate supervision and monitoring of the screening process. To evaluate impact, organised programmes also require ascertainment of the population disease burden. Population-based programmes identify and personally invite each eligible person in the target population to attend a given round of screening. Quality assurance consists of the management and coordination of the programme throughout all levels of the screening process (invitation, testing, diagnosis and follow-up of screen-positives) to assure that the programme performs adequately and provides services that are effective and in-line with programme standards.

The EU guidelines state that coverage of the target population by screening tests should be calculated as the number of women screened at least once in the defined screening interval divided by the number of resident women in the target population. The estimates can be further broken down by invitation and programme status (whether the test was performed within the organised programme) [6]. Compliance to screening invitation should be calculated as the number of invited women in a given period who were screened divided by the number of invited women in that period. The guidelines further recommend that a cut-off date of six months after the end of the period should be used to determine whether the woman attended in response to invitation and that

Table 1
Summary of country response status and screening programme status details.

Country	Historical cervical cancer incidence*	Current cervical cancer incidence**	Change in cervical cancer incidence***	Data submitted	Survey respondent affiliation	Publicly mandated programme	Organised programme	Population-based programme	Description of the current screening situation, including implementation and data compilation responsibilities
Austria	8.7 (1998–2002)	5.8	−2.9	Yes	Professional organisation	Yes	No	No	Screening is opportunistic and guidelines for cervical cancer screening are updated on a regular basis by the national academic societies of gynaecology and cytology/pathology. There is voluntary quality control managed by the Austrian Society of Cytology
Belgium	6.6–8.7 (1998–2002)	8.6	−0.1 to 2.0	Yes	Research	No****	Variable by community	No	There has been a serious attempt to organise screening in the Flemish community and an intention to start organised screening in accordance to the 2008 EU guidelines in 2013. Screening is exclusively opportunistic in the French and Germanophonic communities
Bulgaria	18.0 (1998–2002)	24.5	6.5	No					
Cyprus	–	4.1	–	No					
Czech Republic	17.6 (1983–1987)	14.1	−3.5	Yes	Registry and professional organisation	Yes	Yes	No	The Cervical Cancer Screening Committee, under the Ministry of Health, is responsible for screening implementation. The screening programme is organised; however, quality assurance of the screening process is in place for testing and diagnosis only and the programme is not population-based. The central statistical unit at the Institute of Biostatistics and Analyses, Masaryk University is responsible for compiling screening data
Denmark	28.3 (1953–1957)	10.6	−17.7	Yes	Department of pathology	Yes	Yes	Yes	Implementation of screening is carried out by a national steering group and then local regional steering groups in the five regions of Denmark. Rollout of the programme is complete. Data compilation occurs in the following manner: when clinicians receive the pathology report electronically, an identical copy of the whole report is sent simultaneously and electronically to the national register, "Patobank"
England	8.2 (1993–1997)	8.5	0.3	Yes	Screening programme	Yes	Yes	Yes	Implementation of screening is overseen by the national office of the NHS Cancer Screening Programs which is responsible for improving the overall performance of the programme by developing systems and guidelines. Primary Care Trusts implement the national guidelines and regional directors of public health are responsible for the quality assurance of the programme in their region. Rollout of the programme is complete. Local Call and Recall services and regional Quality Assurance Reference Centers are responsible for data compilation
Estonia	14.2 (1983–1987)	19.9	5.7	Yes	Research	Yes	Yes	Yes	The Cancer Screening Foundation, the Estonian Health Insurance Fund and the National Institute for Health Development are responsible for screening programme implementation. There is currently no defined quality assurance structure and supervision of the screening process. Rollout of the programme is complete. Medical facilities participating in the screening programme are responsible for documenting and archiving screening data, additional studies and their results

Finland	15.9 (1959–1961)	4.3	−11.6	Yes	Registry and research	Yes	Yes	Yes	The Mass Screening Registry (MSR, part of the Cancer Registry) and, in some regions, the cytopathology laboratory advise municipalities in the region on the screening process. The MSR has the status of an expert organisation rather than an authority with a supervisory mandate with regard to following guidelines and procedures. Rollout of the programme is complete. The national data (including regional and local components) is stored and presented by the MSR
France	16.4–18.2 (1975–1977)	8.8	−7.6 to −9.4	Yes	Public health department	Yes	Yes	Yes	Screening implementation is carried out by the ministry of health and the National Cancer Institute at the national level and monitoring centres at the local level. Evaluation is completed by the Institute of Public Health Surveillance at the national level and the monitoring centres at the local level. Rollout of the programme is the piloting and planning phase. The Institute for Public Health Surveillance (InVS) is responsible for compiling screening data
Germany	31.3–34.6 (1968–1972)	8.2	−23.1 to −26.4	Yes	Ministry of health	Yes	No	No	Screening is opportunistic and decentralised. However, at the federal level, quality assurance data are collected and some local health insurance funds and gynaecologists invite their insured members/patients
Greece	–	5.2	–	Yes	Research and professional organisation	No[****]	No	No	Screening is opportunistic. Pap smears are offered for free to women ages 20–65 at public hospitals and health centres and informed of their results by mail but no organised follow-up of individual women. In general, there is no organisation of the programme, monitoring or quality control. There have been regional initiatives to organise screening and the Ministry of Health has started a pilot study on screening based on a call-recall system
Hungary	12.3–21.2 (1962–1966)	18.0	−3.2 to 5.7	Yes	Research	Yes	Yes	Yes	The Office of the Chief Medical Officer within the National Screening Coordination Department is responsible for implementation. Rollout of the programme is complete. The National Screening Registry compiles screening data
Iceland	16.2 (1955–1963)	7.9	−8.3	Yes	Cancer society	Yes	Yes	Yes	The Icelandic Cancer Society is responsible for programme implementation and rollout of the programme is complete. The Steering Office of the Cancer Detection Clinic is responsible for compiling data
Ireland	8.3 (1994–1997)	13.6	5.3	Yes	Screening programme	Yes	Yes	Yes	The National Cancer Screening Service is responsible for implementation and rollout of the programme is complete. The Program Evaluation Unit compiles screening data
Italy	11.7 (1976–1977)	6.7	−5.0	Yes	Research	Yes	Yes	Yes	Screening implementation is carried out by teams based at the regional level whose institutional affiliations differ between regions. Exact rules and standard operative procedures are defined the regional level and vary with regard to level of comprehensiveness. There is no requirement to ascertain the burden of disease in the population to monitor and evaluate the programme. However, there is a National Centre for Screening Monitoring. Rollout is complete in some regions and ongoing in others. Each regional centre checks their own data and the national centre compiles and checks data received from regions

(*continued on next page*)

Table 1 (*continued*)

Country	Historical cervical cancer incidence*	Current cervical cancer incidence**	Change in cervical cancer incidence***	Data submitted	Survey respondent affiliation	Publicly mandated programme	Organised programme	Population-based programme	Description of the current screening situation, including implementation and data compilation responsibilities
Latvia	11.3 (1983–1987)	17.3	6.0	Yes	Research and ministry of health	Yes	Yes	Yes	Conflicting information was submitted regarding the level of organisation of the screening programme. Sources agreed that rollout was complete but disagreed on whether following comprehensive guidelines were required, the status of the quality assurance activities, and whether ascertaining disease burden was required for monitoring and evaluation. The National Health Service was described as being responsible for implementation and data compilation
Liechtenstein	–	–	–	Yes	Public health department	Yes	No	Yes	The programme is not organised - there is no team responsible for implementation, no requirement of following guidelines, no defined quality assurance and no requirement of ascertaining disease burden for monitoring and evaluation. Rollout of the programme, is, however, complete
Lithuania	13.2 (1988–1992)	26.1	12.9	Yes	Ministry of health	Yes	Yes	Yes	The Ministry of Health is responsible for programme implementation as well as data compilation. There is no defined quality assurance structure or supervision of the screening process. No information on who is responsible for data compilation. Rollout of the programme is ongoing
Luxembourg	–	4.9	–	Yes	Ministry of health	No****	No	No	Screening is carried out through a non-systematic National Cervical Cancer Screening Program which is based on a collaboration of gynaecologists and general practitioners. There is one central division of clinical cytology within the National Health Laboratory which is responsible for smear interpretations and programme administration
Malta	7.1 (1969–1972)	3.8	−3.3	Yes	Ministry of health	No	No	No	The National Cancer Plan 2011–2015 includes an action plan for the introduction of a population-based organised cervical cancer screening programme in 2014. The coordination, supervision and responsibility for the proposed programme will be incorporated into the current national screening programme efforts
Netherlands	7.1 (1989–1992)	5.9	−1.2	Yes	Public health department	Yes	Yes	Yes	The National Institute for Public Health and the Environment is responsible for programme implementation. There is no requirement for ascertaining population disease burden to monitor and evaluate the programme. Rollout of the programme is complete. Regional coordinating pathologists are responsible for compiling screening data
Northern Ireland	7.9 (1993–1997)	7.6	−0.3	No					
Norway	15.3 (1959–1961)	9.8	−5.5	Yes	Cancer registry	Yes	Yes	Yes	The Cancer Registry of Norway is responsible for implementation and steering groups oversee quality assurance. Rollout of the programme is complete
Poland	19.4–38.3 (1965–1966)	12.2	−7.2 to −26.1	Yes	Screening programme	Yes	Yes	Yes	The Central Coordinating Office for Coordination of the Programs of Early Detection of Breast Cancer and Prevention and Early Detection of Cervical Cancer along with regional coordinating offices are responsible for programme implementation. Service providers are required to follow comprehensive guidelines but not operating procedures as they are not part of the screening programme and are not regulated by screening guidelines. Rollout of the programme is complete. Data compilation is performed automatically and data are analysed by coordinating offices

Portugal	12.5 (1998–2002)	9.0	−3.5	No					
Romania	34.8 (1967)	28.6	−6.2	Yes	Screening programme	Yes	Yes	Yes	One National and 8 Regional Management Units are responsible for programme implementation. Rollout of the programme is on-going. The Management Unit is responsible for data compilation
Scotland	12.4 (1963–1966)	8.9	−3.5	Yes	Research	Yes	Yes	Yes	The programme is monitored by the National Screening Coordinator within the National Services Division of the Scottish NHS. Each NHS region is then responsible for delivery of the programme and reports to the national coordinator. Rollout of the programme is complete. Some of the data submitted are compiled from raw data extracted from SCCRS or NCCIAS and some data are compiled by regional Screening Coordinators and by designated individuals within each national quality assurance (QA) group
Slovakia	14.0 (1973–1977)	16.1	2.1	No					
Slovenia	26.2 (1956–1960)	10.5	−15.7	Yes	Ministry of health	Yes	Yes	Yes	The National Organized Cervical Cancer Screening Program ZORA, at the Epidemiology and Cancer Registry Department at the Institute of Oncology Ljubljana is responsible for programme implementation. Rollout of the programme is complete. The National Cervical Cancer Screening Registry ZORA (ZORA registry) at the Institute of Oncology Ljubljana is responsible for compiling data
Spain	6.2 (1991–1992)	7.8	1.6	Yes	Research	No****	No	No	Screening is opportunistic with some regional attempts to organise population-based screening
Sweden	17.2 (1959–1961)	7.4	−9.8	Yes	Research and screening programme	Yes	Yes	Yes	21 county screening offices, 6 Regional Cancer Centers (RCC), and one RCC national coordination group are responsible for programme implementation. Rollout of the programme is complete. The Swedish National Cervical Screening Registry is responsible for data compilation and effect monitoring. Screening process data collected regionally and then analysed nationally
Switzerland	16.1 (1970–1972)	3.6	−12.5	Yes	Public health department	No	No	No	Screening is opportunistic with recommendations for screening ages, intervals and follow-up procedures published by the Swiss Society for Gynaecology and Obstetrics
Wales	–	–	–	Yes	Screening programme	Yes	Yes	Yes	Cervical Cancer Wales is responsible for implementation of the programme. Rollout of the programme is complete. The Screening Division Informatics Team is responsible for data compilation

* Oldest available incidence per 100,000 estimates from IARC's Cancer Incidence in Five Continents, Cervix uteri (C53), age [0–85+] (http://ci5.iarc.fr/CI5i-ix/ci5i-ix.htm). Applicable year noted in parentheses for the estimate (either national or regional), ranges given for countries reporting by region within a similar timeframe. The oldest estimate available for Germany is from East Germany (former GDR), 36.0 (1964–1966).

** Age-standardised rates per 100,000 (world) obtained from GLOBOCAN 2012, Estimate Cancer Incidence, Mortality and Prevalence Worldwide in 2012 (available here: http://globocan.iarc.fr/Pages/online.aspx). Age-standardised rates (world) rates obtained for The Netherlands, Northern Ireland and Scotland (1998–2002) from IARC's Cancer Incidence in Five Continents Vol. 9 Cervix uteri (C53), age [0–85+] (available here: http://ci5.iarc.fr/CI5i-ix/ci5i-ix.htm). Estimate from England is for 2006–2008 (from survey response).

*** Negative numbers indicate a decrease, positive numbers indicate an increase.

**** Data from other sources indicated that most of the countries lacking publicly mandated cervical screening programmes in the present survey may actually fulfil the minimum criteria for national or regional programmes (14, 17).

any cut-off date greater than 6 months should be specified [6]. Quality indices of screening registries were taken from Parkin and Bray. These indicators are: Comparability, referring to the standardisation of coding and classification systems; Completeness, the extent to which data on samples taken in the population are recorded in a registry database; Validity, the accuracy of the information recorded in the registry; and Timeliness, the rapidity with which a registry can collect, process and report sufficiently reliable and complete data [16,17].

3. Results

Of the 34 countries contacted, 31 countries responded and 29 countries submitted data (Table 1). Responses came both from the research community (six countries), from ministries of health (five countries), from the screening programmes (five countries) and from public health departments (four countries). Cervical cancer incidence had decreased over the past decades in the majority of countries and increased or stayed steady in the remaining countries. Status of the cervical cancer screening programme was examined using questions regarding whether the screening was offered through a publicly mandated programme, whether the programme was organised, and whether it was population-based. Based on their responses to these questions, countries were then asked to provide further details on the following: the programme mandate and financing, the team responsible for implementation, requirements for service providers to follow comprehensive guidelines, rules and standard operating procedures (SOP), quality assurance structures and supervision and monitoring of the screening process, invitation procedures and status of implementation rollout as well as the target population, screening interval and test used. A text description of screening efforts in each country that responded is provided in Table 1. Information on who is responsible for implementing the screening programme and compiling screening data collected through programme as well as the extent of programme roll-out, and whether the programme is required to follow guidelines and SOPs is also included where available. These details on programme implementation highlight different country-specific contexts and strategies for coordinating screening efforts.

Cervical cancer screening was offered to women through an organised programme in 20 countries and through a publicly mandated programme in 21 countries (Table 1). There was no publicly mandated programme in operation in five countries (Luxembourg did not report whether there was a mandate for the programme). All except one of the countries (Czech Republic) that reported having a publicly mandated and organised programme, also reported that the programme was population-based. Austria, Germany and Switzerland reported having only opportunistic testing. The programmes in Germany and Austria were publicly mandated and a new German screening law sets a deadline for transition to organised screening. Opportunistic testing with ongoing or recent efforts to organise screening, usually at the regional level were reported from Belgium, Greece, Malta and Spain. Belgium reported that organisation status varied by community with significant efforts in the Flemish community to organise screening.

With regard to screening programme details, the recommended screening interval ranged from 1 year (Czech Republic) to 5 years (Estonia, Finland, Netherlands and Romania) and the target ages ranged from a starting age of 17 (Liechtenstein) to a stopping age of 70 (Latvia) (Table 2). In seven countries, the screening interval was age- or test-dependent. The majority of countries reported that the main criterion for excluding women from screening was if they did not have a cervix. A minority of countries reported excluding women who had had a recent opportunistic smear. Proof of having health insurance was required for screening in Estonia and Poland. Financing was allocated directly from the health departments and national health insurance funds or through regional health care budgets. Only a few countries (Iceland, Latvia, Norway and Sweden) required co-payments from the women (either in the whole country or in part of the country). Only five countries relied on a single type of health care provider for the taking of the smears whereas the remaining countries used a mixture of general practitioners, primary care nurses, midwives and gynaecologists for sample-taking. Conventional cytology was used in nine countries, liquid-based cytology (LBC) in 7 and a combination of both conventional and LBC was used in 5 countries. Seven countries did not use HPV testing at any level in the programme. A few programmes have begun to implement primary HPV screening. The majority of programmes use HPV testing as a triage for cytological abnormalities and test of cure following treatment.

Quality assurance programmes for screening were established in all but three countries (Estonia, Liechtenstein and Lithuania) (Table 3). The quality assurance programme was implemented at the national level in seven countries and at the regional level in two countries. In the remaining countries, quality assurance efforts were implemented at two or more levels (local, regional and/or national). In three countries no individual level data were systematically collected (Czech Republic, Estonia and Liechtenstein) while in the remaining countries, individual level cytology and histology data were collected at the regional or national levels. Comprehensive mass screening registries were in place in all but four countries (Estonia, Liechtenstein,

Table 2
Screening programme details among countries reporting a mandated programme.

Country	Exam interval and age-range	Eligibility criteria	Financing source	Co-payment	Sample taker	Screening test used	Status of HPV testing use
Czech Republic	1 year	All adult women	Public health insurance	No	Gynaecologist	Conventional cytology	Not in use
Denmark	3 years (ages 23–49) 5 years (ages 50–65)	Age-eligible women with a cervix in situ, total hysterectomy for benign reasons excluded	Public financing	No	General practitioner Gynaecologist	LBC	Triage Test of cure Self-test* Programme exit test
England	3 years (ages 25–49) 5 years (ages 50–64)	Age-eligible women with a cervix in situ	Primary Care Trusts through the Department of Health	No	General practitioner Primary care nurse	LBC	Triage Test of cure
Estonia	5 years (ages 30–59)	Age-eligible women with health insurance	Health Insurance Fund	No	Midwife	Conventional cytology	Not in use
Finland	5 years (ages 30–60)	Some regional variation in age-range	Municipality health care budget	No	Primary care nurse Midwife	Conventional cytology	Primary screening* Triage Test of cure**
France	3 years (ages 25–65)	Age-eligible women with a cervix in situ and have had intercourse	Health Insurance Plan, Ministry of Health, National Cancer Institute	Unknown	General practitioner Midwife Gynaecologist	Conventional cytology LBC	Triage Primary screening*
Hungary	3 years (ages 25–65)	Age-eligible women who have not participated in opportunistic screening	Health Ministry, National Health Insurance Fund Administration	No	Primary care nurse* Gynaecologist	Conventional cytology	Not in use
Iceland	2 years (ages 20–39) 4 years (ages 40–69)		Department of Welfare	Yes	General practitioner Gynaecologist	Conventional cytology LBC	Not in use
Ireland	3 years (ages 25–44) 5 years (ages 45–60)	Immunosuppressed women start at age 20	Department of Health	No	A mix of health care providers	LBC	Test of cure
Italy	3 years cytology 5 years HPV (ages 25–64)	Age-eligible women with other health concerns excluded and women who have attended opportunistically	Regional health funds	No	Primary care nurse Midwife	Conventional cytology LBC	Primary screening Triage Test of cure
Latvia	3 years (ages 25–70)	Age-eligible women who do not have a recent state-paid smear, women who have not had a hysterectomy, women who have not had a smear for other reasons	Health care budget	Yes	General practitioner Gynaecologist	Conventional cytology	Not in use
Liechtenstein	2.5 years (older than 17)		Governmental funding	No	General practitioner Gynaecologist	LBC	Primary screening Co-testing Triage
Lithuania	3 years (ages 25–60)	Age-eligible women without insurance excluded	National Health Insurance Fund	No	General practitioner Midwife Gynaecologist	Conventional cytology	Not in use
Netherlands	5 years (ages 30–60)	Age-eligible women with a cervix in situ, women without a recent smear for other indications, not currently pregnant	Ministry of Health, Welfare and Sport	No	General practitioner Primary care nurse	Conventional cytology LBC	Triage

(*continued on next page*)

Table 2 (*continued*)

Country	Exam interval and age-range	Eligibility criteria	Financing source	Co-payment	Sample taker	Screening test used	Status of HPV testing use
Norway	3 years (ages 25–69)	Age-eligible women with a cervix in situ, women without a recent opportunistic smear	Cancer registry	Yes	General practitioner Gynaecologist	Conventional cytology LBC	Triage
Poland	3 years (ages 25–59)	Age-eligible women with a cervix in situ, women must have an identify card and proof of health insurance	National Healthcare Fund	No	Midwife Gynaecologist	Conventional cytology	Triage
Romania	5 years (ages 25–64)	Age-eligible women with a cervix in situ	Ministry of Health	No	General practitioner Gynaecologist	Conventional cytology	Not in use
Scotland	3 years (ages 20–60)	Age-eligible women with a cervix in situ, temporary exclusions for a variety of conditions	Governmental funding allocated to regional level Health Authorities	No	General practitioner Primary care nurse Midwife Gynaecologist	LBC	Test of cure
Slovenia	3 years (ages 20–64)	Age-eligible women with a cervix in situ	Health Insurance Institute of Slovenia	No	Gynaecologist	Conventional cytology	Triage Test of cure
Sweden	3 years (ages 23–50) 5 years (ages 50–60)	Age-eligible women with a cervix in situ	Regional health funds	Varies by region	Midwife	Conventional cytology LBC	Triage Test of cure Primary screening*
Wales	3 years (ages 25–50) 5 years (ages 50–64)		National Health Service	No	General practitioner Primary care nurse Midwife Gynaecologist	LBC	Triage Test of cure Other***

* In research/programme pilots.
** Clinical practice in some colposcopy units, not necessarily used in the organised programme.
*** Resolution of uncertainty, e.g. persistent low grade dyskaryosis.

Table 3
Status of quality assurance (QA) activities

Country	Level of QA programme implementation	Individual level data collected	Data QA and analysis systems	Mass screening registry	Opportunistic screening data collection	Programme annual report
Czech Republic	National/local	No, anonymised at the national level	Yes, both	Yes	Data not collected, opportunistic defined as outside the network of accredited cytology labs	Yes
Denmark	National/ regional	Yes, cytology, histology and HPV tests collected at the national level	Yes, both	Yes	Opportunistic screening stored in same manner as organised screening data	Yes
England	National coordination, local management	Yes, cytology, histology and HPV tests collected at local level for programme operations	Yes, both	Yes	Opportunistic screening stored in same manner as organised screening data	Yes
Estonia	No QA programme	No data collected systematically	No	No	Medical facilities are responsible for documenting and archiving both opportunistic and organised screening test results	No
Finland	National	Yes, cytology, histology and HPV tests collected at the national level	Yes, both	Yes	Opportunistic screening data not included systematically in screening registries	Yes
France	National/local	Yes, cytology, histology and HPV tests collected at the district level	Yes, both	Yes	Opportunistic screening stored in same manner as organised screening data	Yes
Hungary	National	Yes, cytology and histology data collected	Yes, both	Yes	Information on opportunistic screening is available from the National Health Insurance Fund Administration	Yes
Iceland	National	Yes, cytology and histology data collected	Yes, both	Yes	Opportunistic screening stored in same manner as organised screening data	Yes
Ireland	National	Yes, cytology, histology and HPV tests collected at the national level	Yes, both	Yes	Opportunistic cytology results not collected, colposcopies resulting from an opportunistic smear are recorded	Yes
Italy	Regional	Yes, cytology, histology and HPV tests from the organised screening programmes collected at the regional level	Yes, both	Not reported	Opportunistic data collection varies across regions	Yes
Latvia	National	Yes, cytology, histology and HPV tests collected	Yes, both	Yes	Opportunistic data stored in same manner as organised screening data	Yes
Liechtenstein	No QA programme	No data collected systematically	No	No	No information	No
Lithuania	No QA programme	Yes, cytology data collected. Regulation in place to collect histology data systematically but not done in practice.	Yes, analysis system	No	No information	Yes
Netherlands	All levels	Yes, cytology, histology and HPV tests collected	Yes, QA system	Yes	Opportunistic data stored in same manner as organised screening data and can be separated from organised screening tests	No
Norway	National	Yes, cytology, histology and HPV tests collected	Yes, both	Yes	All data is stored in the same fashion	Yes
Poland	Regional	Yes, cytology and histology data collected	Yes, both	Yes	Opportunistic data not registered in the programme database, data from opportunistic testing is stored by individual cytology labs	Yes
Romania	National/ regional	Yes, cytology and histology data collected	Yes, both	No	Data from programme and opportunistic testing recorded at individual labs	No

(*continued on next page*)

Table 3 (*continued*)

Country	Level of QA programme implementation	Individual level data collected	Data QA and analysis systems	Mass screening registry	Opportunistic screening data collection	Programme annual report
Scotland	National/ regional	Yes, Scottish Cytology Call Recall System holds information on cytology, histology and HPV tests within individual electronic patient records	Yes, both	Yes	Opportunistic data stored in same manner as organised screening data	Yes
Slovenia	National	Yes, cytology, histology and HPV tests collected	Yes, both	Yes	Opportunistic data stored in same manner as organised screening data. By law, a copy of all reports must be sent to the register	Yes
Sweden	National	Yes, cytology, histology and HPV tests collected	Yes, both	Yes	Opportunistic data stored in same manner as organised screening data and can be separated from organised screening tests	Yes
Wales	National/ regional/local	Yes, cytology, histology and HPV tests collected	Yes, both	Yes	Opportunistic data stored in same manner as organised screening data	Yes

Lithuania and Romania). In the Czech Republic, anonymised data are reported at the national level. Individual level data on both opportunistic and organised sample-taking were collected in 10 countries.

Population coverage of the screening test ranged from less than 10% in Hungary and 13% in France to 70% or more in Denmark, England, Finland, Iceland, Ireland, Italy, Scotland, Slovenia, Sweden and Wales, as calculated and submitted by the individual countries (Table 4). Some variation in coverage calculation methodology may impact the comparability of these estimates. The proportion of tests taken outside of the organised programme could not be estimated by all countries but estimates ranged from as low as 1.2% in England to as high as 60% in Finland and 80% in Estonia. These estimates were provided by the countries; the survey did not include a standard method on how to estimate this and descriptions of how these estimates were derived were not requested. Countries were asked to describe how coverage and compliance were calculated in their programmes. The methods used for calculating coverage were provided by all but two countries (Liechtenstein and Romania). Compliance was calculated in all but five countries (Czech Republic, Latvia, Liechtenstein, Norway and Slovenia). In Norway and Slovenia, a reminder-based invitation system is used where only women who have not attended in the recommended interval are sent an invitation. Therefore, compliance is not calculated in Slovenia and attendance following reminder(s) is calculated in Norway.

Call and recall invitation systems are generally managed at the regional or national level, although systems varied across regions/municipalities in some countries. Population registers, either national or regional/municipal are used in the majority of countries to generate invitation lists; however, insurance information is used in Estonia, Hungary, Lithuania and Poland, family doctor lists are used in Romania, and population registers in conjunction with health care databases are used in Italy and Latvia. In Slovenia, women themselves are responsible for making a screening appointment and gynaecologists or the central coordination office invite women if they do not attend within the interval (Table 4). Countries were further asked who oversees and carries out the referral process. In 10 countries (Czech Republic, Denmark, Estonia, France, Hungary, Latvia, Lithuania, Netherlands, Romania and Slovenia), this was done by the healthcare service provider (general practitioner, gynaecologist, midwife or other smear-taker) and in eight countries the referral process was overseen and carried out as part of programme-level administration (Finland, Iceland, Ireland, Italy, Poland, Scotland, Sweden and Wales). General practitioners handle referrals in England unless it is a direct referral, in which case it is the responsibility

Table 4
Invitation responsibility and invitation data sources and the estimates of test coverage and proportion of tests outside the organised programme that were provided by the countries.*

Country	Entity responsible for invitations to screening and data source used for invitations	Test Coverage	Proportion of tests outside organised programme	Calculation of coverage
Czech Republic	No individual invitations sent	55%	Not available	Number of women screened at least once in one year divided by number of resident women in the target population
Denmark	The Danish Pathology Databank (Patobank) sends all invitations on a national level to the target population as well as up to two recalls to non-responders in a 3 month interval	75%	10%	Number of screened woman out of all women in the past 43 months for 23–49 of age and the past 66 months for 50–64 of age according to the recommended interval of 3 or 5 years respectively according of the target population from 23–64 years.
England	Invitations are sent through locally managed Call and Recall Services using data obtained from the National Health Applications and Infrastructure Services (NHAIS)	74% and 78%**	1.2%	(1) Number of women aged 25–49 who have had an adequate screening test within the last 3.5 years (2) Number of women aged 50–64 who have had an adequate screening test within the last 5 years divided by (1) Eligible female population aged 25–49 (2) Eligible female population aged 50–64
Estonia	The Estonian population registry and Estonian Health Insurance Fund are used as the source data for invitations. The National Institute for Health Development is responsible for sending invitations	35%	80%	Number of women screened at least once in the defined interval divided by number of resident women in the target population
Finland	Municipalities are generally responsible for invitations; however, they can choose to purchase invitation services and the sample-taking units are responsible for mailing. Data regarding the target population are obtained from the population register and usually transferred to the sample-taking units by the MSR	70%	60%	Women invited (coverage), or women screened per year/period divided by number of women resident in area per year
France	The monitoring centres are responsible for invitations	13%	Not available	The numerator is the number of women screened at least once in 1 year and 3 years. Two denominators are used: (1) the estimated number of resident women ages 25–65 calculated by the National Institute of Statistics and economic studies for the defined period; (2) the same denominator without (i) the permanent medical exclusions (declared by women or found in hospital discharge) and (ii) the deaths***
Hungary	The invitation letter is issued by the National Screening Registry (being established as part of the National Screening Coordination Department). A population list from National Health Insurance Fund Administration (OEP) is used to determine the invitation list	<10%	A greater proportion than within the programme	Number of women who accepted the offered screening divided by the number that received an invitation letter
Iceland	The Icelandic Cancer Detection Clinic of the Icelandic Cancer Society is responsible for invitations and data regarding the screening population are collected in an Oracle database	72–75%	40%	Women that at the end of each year have attended during the last 3 years divided by the women in the invited cohort
Ireland	Cervical Check system sends out invitations and database for invitations is generated from the Department of Social Welfare information as well as self-registrations	70%	Very few	Number of unique women screened at least once in defined interval divided by women in the target population

(*continued on next page*)

Table 4 (*continued*)

Country	Entity responsible for invitations to screening and data source used for invitations	Test Coverage	Proportion of tests outside organised programme	Calculation of coverage
Italy	Invitation systems vary by region. For example, the unit for screening organisation and evaluation may send invitations using a common computer programme and a regional population database drawn from the population registry of the municipalities and databases of the local health unit	75%	50%	Coverage is not routinely directly calculated given the large opportunistic activity. Coverage is estimated by interviewing a sample of women. The number of women screened at least once in 3 years is divided by the number of resident women in the target population
Latvia	The National Health Service is in charge of Organized Cancer Screening programme. The main source of information is the Population Register and the "Vadibas Informacijas Sistema" (VIS) data base (which contains all health care data)	59%	41%	Organised and opportunistic cytology tests in a year divided by the cervical cancer screening target group in that year
Liechtenstein	The Public Health Department is in charge of sending invitations using data from the Central registry	Not reported	Not reported	Not reported
Lithuania	The Primary Health Care (PHC) institutions are responsible for sending invitations. The data are obtained from patient data bases of the PHC institutions which are synchronised with the registry of insured persons of NHIF	Approx. 40%	Not reported	Number of women screening in a defined interval divided by the number of eligible women in the target population
Netherlands	Individual invitations are sent by the five regional Screening Organizations in the Netherlands. Eligible women are identified by these Screening Organizations through the municipal population register	73–82%	9%	The number of women screened at least once during the 5-year interval of interest divided by the number of women resident in the target population in the most recent year of the 5-year interval
Norway		67%, 75%, and 84%[****]	Not applicable	The number of women screened at least once during the interval (3.5, 5, or 10 years) divided by the number of women in the population register at the end of the year at the end of the interval (excluding women who have had gynaecology cancer and women who do not have a cervix in situ)
Poland	Regional Coordinating Offices are responsible for sending invitations using data from the national SIMP database hosted by National Healthcare Fund	25%	An estimated 2/3 of all Pap smears are taken outside the programme	The number of Pap smears taken in the given year registered in the SIMP database divided by the number of women ages 25–59. Since SIMP is used as a tool for reimbursement, the numerator probably includes repeated smears as well
Romania	Regional Management Units invite women through family doctors lists	20% (regional pilot)	Not applicable	Not reported
Scotland	Invitations are sent from a central NHS Scotland data centre and printed automatically from the national screening computer	79% and 73%[*****]	Very few, but figures not available	Number of women ages 20–60 screened within the last 3.5 and 5.5 years, respectively, divided by the number of eligible women ages 20–60. Eligible women are those with a cervix who do not have a current exclusion
Slovenia	Cervical cancer screening is integrated within the primary health care services. Women ages 20–64 are expected to make appointment for the cervical cancer screening visit with their personal gynaecologist every 3 years. Gynaecologists monitor attendance of their women and if no appointment is made, they send a standardised and personalised invitation with information and a recall invitation if needed. If no cervical smear is registered after 4 years, the central co-ordination office at the Institute of Oncology Ljubljana sends an invitation and recall invitation if needed. The ZORA registry is linked to the Central Population Register to ensure complete coverage	72%	All smears are regarded as taken within the programme	Number of women with at least one smear in three consecutive years divided by the number of resident women in the target population

Table 4 (*continued*)

Country	Entity responsible for invitations to screening and data source used for invitations	Test Coverage	Proportion of tests outside organised programme	Calculation of coverage
Sweden	The screening group in each county (usually located at the public hospital cytology laboratory or at the Regional Cancer Center, as is the case in Stockholm and Gothenburg) is responsible for invitations	78% and 84%**	35%	Number of women in a specific age group and geographic region that have taken a screening test in a defined time-period divided by the mean population of women in the corresponding age group, time-period and region. Coverage is calculated at 3.5 year and 5.5 year intervals, respectively, to account for the fact that the invitation is sent once 3 and 5 years, by age group respectively, have passed since the last smear
Wales	Cervical Screening Wales is responsible for sending invitations and data are obtained from the national NHS database – the Exeter (NHAIS) call and recall system	77% and 80%**	14%	Number of women who have an adequate test reported within the defined interval (3 or 5 years) divided by the number of women resident who are eligible for cervical screening (not ceased for clinical reasons)

* Please note that since screening intervals and target age groups differ between countries, test coverage figures are not directly comparable between countries (even if they use the same method to estimate test coverage).
** Younger and older age groups, respectively.
*** If the experimental monitoring centres are perpetuated, a 5-year interval will be calculated. Currently, the 5-year interval is calculated in one monitoring centre that covers two districts.
**** In the last 3.5, 5 and 10 years, respectively.
***** In the last 5.5 years and 3.5 years, respectively (among women ages 20–60 with a cervix).

of the laboratory. Median turnaround time from an abnormal result to colposcopy was requested to gain further data on the referral process. The results varied across countries. Median time to colposcopy was not available or was available but difficult to obtain in eight countries (Czech Republic, Estonia, France, Latvia, Lithuania, Romania, Scotland and Slovenia), varied by region in two countries (Denmark and England) and depended on lesion severity in four countries (Finland, Ireland, Italy and Wales). Four countries provided numerical estimates on the median time (Hungary, Iceland, the Netherlands, Poland and Sweden) which varied from 2 weeks to 75 days.

In general, country calculation methods were in-line with recommendations for calculating coverage and included further descriptions of excluded populations

Table 5
Quality assurance (QA) indicators evaluated for the screening registries.*

Country	Comparability	Completeness	Validity	Timeliness
Czech Republic	Yes	Yes	Yes	Yes
Denmark	Yes	Yes	Yes	Yes
England	Yes	Yes	Yes	Yes
Estonia**	No	No	No	No
Finland	Yes	Yes	Yes	Yes
France	Yes	No	No	No
Hungary	No	No	Yes	No
Iceland	Yes	Yes	Yes	No
Ireland	Yes	Yes	No	Yes
Italy	Yes	Yes	Yes	Yes
Latvia	Yes	Yes	Yes	Yes
Liechtenstein**	No	No	No	No
Lithuania**	No	No	No	No
Netherlands	Yes	Yes	Yes	Yes
Poland	Yes	Yes	Yes	No
Romania	Yes	No	Yes	Yes
Scotland	Yes	Yes	Yes	Yes
Slovenia	Yes	Yes	Yes	Yes
Sweden	Yes	Yes	Yes	Yes
Wales	Yes	Yes	Yes	Yes

* No information submitted for Norway on these indicators.
** No system in place for programme/data quality assurance (QA).

and accommodations for different screening intervals for different age groups. Similarly, the majority of countries calculated compliance according to the guidelines. Many countries also specified alternate cut-off dates (Denmark, France, Italy, Netherlands, Sweden and Wales).

Countries were also asked how they avoid excessive sample-taking. Among countries that have strategies in place to address excessive sample-taking (15 of the countries), the most common approach was to limit reimbursements for, or analysis and registration of, samples taken outside the recommendations (Czech Republic, England, Ireland, Lithuania, Scotland, Slovenia). Other main strategies included limiting invitations or samples taken outside the interval (Denmark, Italy, Latvia and Sweden) checking population data-lists for attendance (Iceland); establishing and ensuring adherence to guidelines and standards (Finland and Wales) and providing information and education on screening (Finland, France and the Netherlands). In Denmark and Sweden, organised and opportunistic smears are integrated in the same database allowing for automatic postponement of the next screening test until the age-specific interval has passed.

Table 5 summarises the quality indices of the screening registries, as evaluated in countries with a publicly mandated programme. While the majority of countries reported using all four of these indices, Estonia, France, Hungary, Liechtenstein and Lithuania reported using only one or none of these indicators.

Cervical cancer case audits are a recommended aspect of programme evaluation and monitoring. Audit activities have been conducted or are on-going in 12 of the countries but only five countries reported using a comparison (control) group in their analyses (Table 6). The results of the audits were used in different ways. While some countries have the results of their audits public and published in research journals, other countries used the results internally and did not make them publically available. Four countries directly reported

Table 6
Status of cervical cancer case audits.

Country	Audits	Comparison group	Results used programmatically	Notes
Czech Republic	No			
Denmark	Yes	No		National numbers will be published for the first in July 2014 concerning the year 2013
England	Yes	Yes	Yes	Audits are completed annually. The results are used programmatically with the aim being to monitor and improve the programme locally
Estonia	No			
Finland	Yes	Yes	No	Audits have been completed through research projects but not regularly scheduled within the programme. The results have been used for lab QA and policy discussions so far
France	No			
Hungary	Yes	Unknown	Unknown	Audits are completed and published by the National Audit Office
Iceland	Yes	No	Yes	The yearly audit is used to reform the screening programme
Ireland	Yes	No	No	Audits are completed through ongoing incident case review. The aim is to determine why the cancer developed and to inform any necessary improvements to the screening programme. Results are not made public
Italy	No			Region-specific efforts to link screening histories and cases have been completed
Latvia	No			
Liechtenstein	No			
Lithuania	No			
Netherlands	Yes	No	No	Audits completely annually, results have yet to be used programmatically and are not made publicly available
Norway	Yes	No	Unknown	Efforts to evaluate cases and screening histories ongoing
Poland	No			
Romania	No			
Scotland	Yes	No		Audits have been completed at the regional level and a national pilot has been underway since 2011. Collated annually and results used locally and made public in regional annual reports
Slovenia	Yes	Yes	Yes	Audits are completed annually and results presented in programme training days and will be published in the next programme report
Sweden	Yes	Yes	Yes	Audits have been completed through research projects with the intention of making them annual. Results are used programmatically through the Regional Cancer Centers and professional organisations
Wales	Yes	Yes		Audits are completed ongoing, with results disseminated in local meetings and through direct communication. The results have been used for educational and service improvement

using the results programmatically and others reported using results for feed-back to screening programme implementers and labs. Our survey focused on audits of cervical cancer cases and controls. Further details on auditing activities could be collected in a more detailed audit-focused report.

Estimating the costs associated with launching, operating, monitoring and evaluating a screening programme was found to be challenging. Given the different structures of each programme and the differing levels of implementation, costs were not easily defined in the overall health budgets. In general, countries were not able to report on the costs by line-items. Instead, they submitted broader comments regarding the costs of the programme organisation. On-going monitoring and surveillance efforts at the local and national levels were often linked with the operational budget of the screening programme, making the estimation of costs for individual activities difficult. Costs for organisation and quality control within the overall screening programme are recommended to be a clearly defined proportion of the overall operating budget, to allow for clear prioritisation of these activities. Cost information on the establishment and maintenance of screening registries was also hard to collect due to, in part, the inter-connectedness of programmes. For programmes that have existed longer, the budgets are more fully integrated in the healthcare budgets. Some newer programmes had to seek funding from other sources or must account for significant start-up costs. The costs of conducting audits were either included in the overall costs of the screening programme management and organised quality assurance (as was the case in England and Slovenia) or financed through research grants (for example, in Finland and Sweden).

4. Discussion

4.1. Main findings and strengths

Previous studies have mostly focused on individual country situations with calculation of country-specific quality control indicators while results from this study provide in-depth descriptions of cervical cancer screening programme implementation as well as the organised quality assurance efforts performed by the programmes. Specifically, we have examined details of screening data collection and analysis, methods for measuring coverage and compliance and the status of conducting audits of the cervical cancer cases and controls. The results demonstrate that organised efforts for quality assurance, monitoring and evaluation are implemented to a different extent across European countries and that key performance indicators, such as coverage and compliance, are not estimated in a comparable manner between most countries. More established programmes can track data from year to year and push out changes through the programme infrastructure (creating feedback loops).

Costs associated with the organisation of programmes were hard to define, which is of concern as this makes it difficult to conduct cost-effectiveness evaluations of different screening and vaccination programme implementation scenarios. The management and budgets of more established screening programmes are closely integrated into other healthcare programmes while newer programmes must build programmes that account for the complexity necessary for effective monitoring and evaluation, but are sustainably linked to existing structures. Perhaps this is an area where standard cost models could be applied and used more consistently for registry monitoring and, more broadly, for comparably evaluating the cost burden of changes to programmes.

4.2. Limitations and other considerations

Despite our efforts to use uniform programme terminology and adhere to definitions outlined in the European guidelines for quality assurance in cervical cancer screening, interpretations of our questions seem to have differed across settings due to how health care systems operate and implement prevention strategies. However, the countries commonly submitted free text comments and we sought as far as possible to clarify their responses and obtain further details. While this made it more difficult to capture standardised information, it allowed for more complete information. Greater standardisation on how performance indicators are calculated and reported could improve comparability of data and facilitate the exchange of experiences between programmes. For example, data from other sources indicated that most of the countries lacking publicly mandated cervical screening programmes in the present survey may fulfil the minimum criteria for such programmes [14,18]. As demonstrated in Table 1, some countries with opportunistic screening have incidence rates on par or lower than countries with programmes. Proving a relationship between the organisational status of the screening programme and cancer incidence or mortality remains difficult and has been an area of discussion as both organised and opportunistic screening efforts have been shown to be effective [1,2,19–21]. That said, organised, population-based programmes have the potential to achieve more efficient resource use and greater equity in systematically reaching the target population [22,23].

Efforts to disseminate the guidelines and encourage countries to implement organised, population-based programmes in-line with the EU recommendations have been ongoing. Focus should be placed on continuous reporting of quality indicators, such as coverage and compliance which were found to be calculated differently across countries, and monitoring incremental optimisation of screening programmes. Active engagement in an on-going optimisation process could bridge the distance between guidelines and research evidence

and the realities of applying new strategies to existing screening structures. Further attention needs to be given to the details of follow-up strategies and the evaluation of whether programme actions are, in fact, leading to positive gains in reducing incidence and mortality. Given the political nature of the survey in examining the extent to which programmes were organised and quality assured, there is a potential for reporting bias. Finally, the responses collected reflect current prevention efforts. Particularly with regard to recent advances in vaccination and HPV testing, the policies used are likely to be changing rapidly.

4.3. Future directions

As screening strategies develop and new technologies are introduced, organised quality assurance and evaluation of new screening methods is critical. Specifically, quality assurance of HPV testing in screening programmes is of increasing importance as more programmes use HPV testing at various levels. The WHO HPV LabNet has launched global proficiency panels for quality control of HPV testing, although this programme has until recently been more focused on HPV genotyping. Clear improvements in the proportion of laboratories reporting proficient results have been reported to occur with continuous use of such quality control measures. In the next iteration of this survey, we intend to collect further information on HPV testing practices and develop further recommendations to ensure quality assured testing. The possibility of establishing biobanks and using biobank data for programme monitoring and evaluation could also be considered. Combined with registry linkages, this would provide more advanced monitoring and development opportunities.

Integration of cervical cancer screening and HPV vaccination programmes is an area of increasing attention as the oldest cohorts of young women vaccinated will shortly enter the screening ages. Determining the optimal screening strategies for HPV-vaccinated cohorts – with regard to screening methods and cost-effectiveness – will be important for the continued success and relevance of screening programmes. Concomitant collection of data also on HPV vaccination programmes will therefore become increasingly important. The results of this survey may help to inform future iterations of the European screening guidelines on organisation and quality control of cervical cancer screening programmes and provide an overview of current screening activities which can be used as a reference point for evaluating screening programme optimisation efforts.

Conflict of interest statement

None declared.

Acknowledgements

The authors would like to acknowledge the effort and time that the survey respondents dedicated to responding to our survey. Thanks to Julietta Patnick, Mari Nygård, Pär Sparén and Bengt Andrae for feedback on the survey structure and content. And sincere thanks to Ahti Anttila for highly useful feedback on the manuscript and expert opinion on the analyses and reported results. This study was funded by the European Union (PREDHICT project, FP7 grant agreement no 242061). The funding agency had no role in the design, execution or interpretation of the study or in the decision to submit it for publication.

References

[1] Laara E, Day NE, Hakama M. Trends in mortality from cervical cancer in the Nordic countries: association with organised screening programmes. Lancet 1987;1(8544):1247–9.
[2] Quinn M, Babb P, Jones J, Allen E. Effect of screening on incidence of and mortality from cancer of cervix in England: evaluation based on routinely collected statistics. BMJ 1999;318(7188):904–8.
[3] Ronco G, Pilutti S, Patriarca S, Montanari G, Ghiringhello B, Volante R, et al. Impact of the introduction of organised screening for cervical cancer in Turin, Italy: cancer incidence by screening history 1992–98. Br J Cancer 2005;93(3):376–8.
[4] van der Aa MA, Pukkala E, Coebergh JW, Anttila A, Siesling S. Mass screening programmes and trends in cervical cancer in Finland and the Netherlands. Int J Cancer 2008;122(8):1854–8.
[5] International Agency for Research on Cancer. Cervix cancer screening. Lyon, France: International Agency for Research on Cancer; 2005.
[6] Arbyn M, Anttila A, Jordan J, Ronco G, Schenck U, Segnan N, et al. European guidelines for quality assurance in cervical cancer screening. 2nd ed. Luxembourg: Office for Official Publications of the European Communities; 2008.
[7] WHO/ICO Information centre on HPV and cervical cancer (HPV Information Centre). Human papillomavirus and related cancers in Europe. Summary report 2010. In. Barcelona, Spain: WHO/ICO HPV Information Centre; 2010.
[8] Arbyn M, Autier P, Ferlay J. Burden of cervical cancer in the 27 member states of the European Union: estimates for 2004. Ann Oncol 2007;18(8):1423–5.
[9] Coleman D, Day N, Douglas G, Farmery E, Lynge E, Philip J, et al. European Guidelines for Quality Assurance in Cervical Cancer Screening. Europe against cancer programme. Eur J Cancer 1993;29A(Suppl. 4):S1–S38.
[10] Council of the European Union. Council recommendation of 2 December 2003 on cancer screening: Office of the European Union; 2003.
[11] Valerianova Z, Panayotova Y, Amati C, Baili P. Cervical cancer screening in Bulgaria–past and present experience. Tumori 2010;96(4):538–44.
[12] Veerus P, Arbyn M, Amati C, Paolo B. Impact of implementing a nationwide cervical cancer screening program on female population coverage by Pap-tests in Estonia. Tumori 2010;96(4):524–8.
[13] Ronco G, van Ballegooijen M, Becker N, Chil A, Fender M, Giubilato P, et al. Process performance of cervical screening programmes in Europe. Eur J Cancer 2009;45(15):2659–70.

[14] Anttila A, von Karsa L, Aasmaa A, Fender M, Patnick J, Rebolj M, et al. Cervical cancer screening policies and coverage in Europe. Eur J Cancer 2009;45(15):2649–58.
[15] Elfstrom KM, Dillner J, Arnheim-Dahlstrom L. Organization and quality of HPV vaccination programs in Europe. Vaccine 2015. http://dx.doi.org/10.1016/j.vaccine.2015.02.028.
[16] Bray F, Parkin DM. Evaluation of data quality in the cancer registry: principles and methods. Part I: comparability, validity and timeliness. Eur J Cancer 2009;45(5):747–55.
[17] Parkin DM, Bray F. Evaluation of data quality in the cancer registry: principles and methods Part II. Completeness. Eur J Cancer 2009;45(5):756–64.
[18] Karsa LV, Anttila A, Ronco G, Ponti A, Malila N, Arbyn M, et al. Cancer screening in the European Union Report on the implementation of the Council Recommendation on cancer screening, 1st Report; 2008.
[19] Gustafsson L, Sparen P, Gustafsson M, Wilander E, Bergstrom R, Adami HO. Efficiency of organised and opportunistic cytological screening for cancer in situ of the cervix. Br J Cancer 1995;72(2):498–505.
[20] Nieminen P, Kallio M, Anttila A, Hakama M. Organised vs. spontaneous Pap-smear screening for cervical cancer: a case-control study. Int J Cancer 1999;83(1):55–8.
[21] Laskey PW, Meigs JW, Flannery JT. Uterine cervical carcinoma in Connecticut, 1935–1973: evidence for two classes of invasive disease. J Natl Cancer Inst 1976;57(5):1037–43.
[22] Espinas JA, Aliste L, Fernandez E, Argimon JM, Tresserras R, Borras JM. Narrowing the equity gap: the impact of organized versus opportunistic cancer screening in Catalonia (Spain). J Med Screen 2011;18(2):87–90.
[23] Arbyn M, Rebolj M, De Kok IM, Fender M, Becker N, O'Reilly M, et al. The challenges of organising cervical screening programmes in the 15 old member states of the European Union. Eur J Cancer 2009;45(15):2671–8.