

Chapter 3

Use of screening for cervical cancer

Delivery and uptake of screening

Cervical cancer screening started with the introduction of the Papanicolaou test into clinical practice. In many countries, this occurred as part of family-planning services, so that the target group was younger women. Because such services are frequently not well integrated with secondary levels of care, it was not always possible to ensure adequate diagnosis and treatment of women with a positive test result. It has now become clear that organized screening programmes have a greater impact than opportunistic screening because they have the potential to achieve greater participation and this can improve equity of access and the likelihood of reaching women at higher risk.

Cervical cancer screening comprises various types of care or services, ranging from provision of the screening test to diagnosis and treatment, as shown in Figure 46.

Implementation of a national programme requires that there be a national policy that defines the screening age and interval and what method of screening will be used, as well as sufficient political and financial investment. The major issues that have to be considered are:

- The budget to run the programme
- Training of health-care providers in: the logic of the screening policy;

carrying out the screening test; patient counselling; and collection and interpretation of monitoring data (participation and follow-up rates)

- Setting up equipment supply systems for the clinic or health centre
- Ensuring that high-quality laboratory services are available
- Establishing a referral pathway for treatment of patients (which may involve training of people at local level and referral for more advanced cases needing specialized treatment)
- Developing the capacity to offer treatment (for *in situ* disease, definitive treatment and palliative care)
- Setting up national monitoring systems
- Education of the population to ensure participation in the screening programme

Overall, a screening programme should be an integrated system in which, as seamlessly as possible, women are recruited, screened, receive and understand the results, are referred for treatment as required, return for repeat screening as determined by the policy and become advocates for others to participate. This means that all staff must know, understand and give the same message to patients, that services be accessible, equipped and welcoming, and that transport and communications mechanisms with institutions for reading of results and treatment are functional. In other words, a functional health system must operate with sufficient coverage, so that all women in the target group have satisfactory access to services.

The organization and financing of the overall health-care system of a

Organized screening programme

- an explicit policy with specified age categories, method and interval for screening;
- a defined target population;
- a management team responsible for implementation;
- a health-care team for decisions and care;
- a quality assurance structure; and
- a method for identifying cancer occurrence in the target population

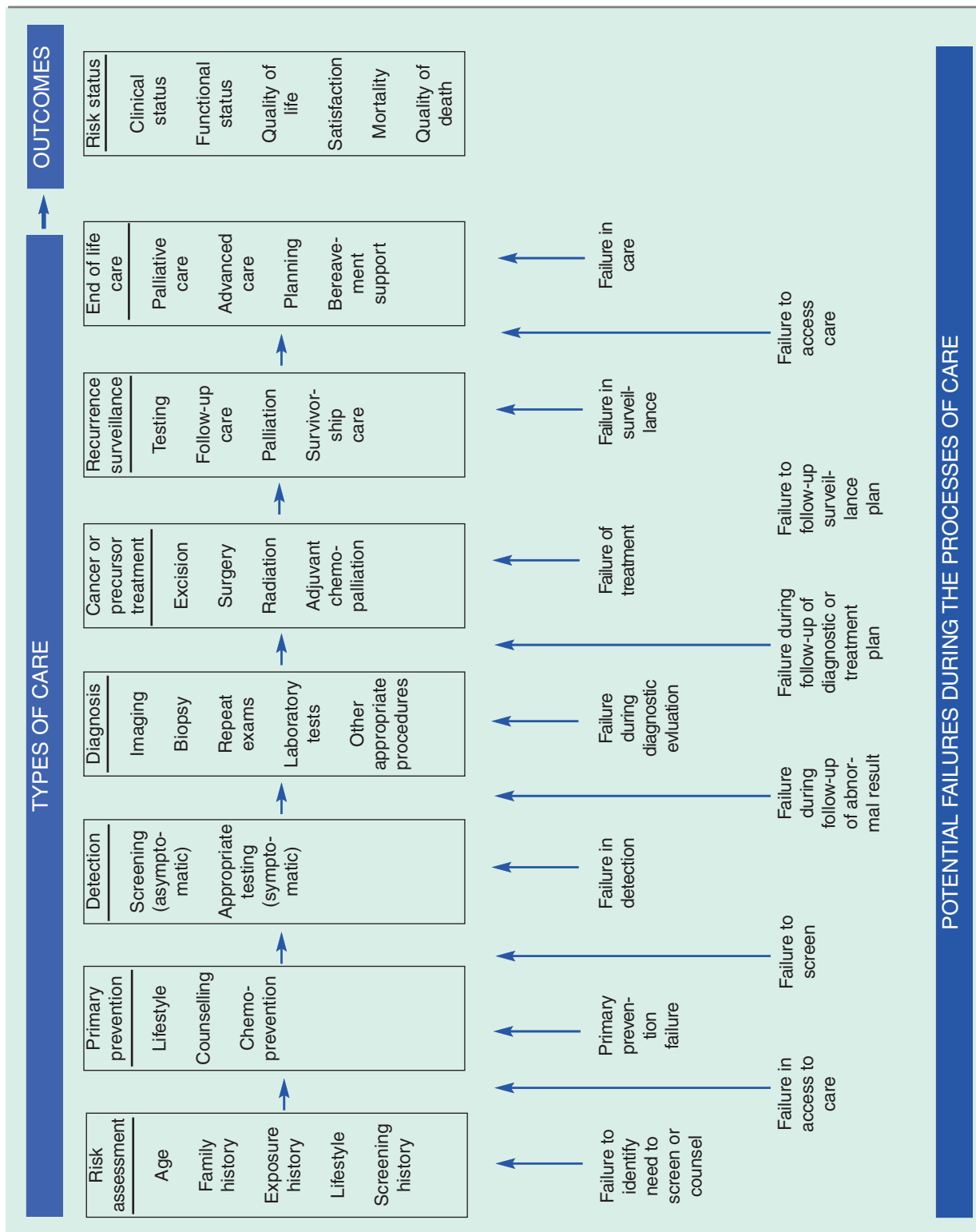


Figure 46 The cervical cancer screening process

From Zapka *et al.* (2003)

country affects the potential effectiveness of a cervical screening programme, in particular if only part of the service is free of charge or covered by insurance (state or other). Further influences on programme effectiveness include the accessibility of services in poorly developed health-care systems and the way that information about the programme is conveyed to the target population.

Europe

Among 38 European countries, 25 are member states of the European Union, which includes all western European countries except Iceland, Norway and Switzerland, and (as of 2004) also several eastern European countries. The European Union includes 450 million inhabitants. Most data on the use of cervical cancer screening are available from western European countries. Despite its relatively good level of resources, Europe has rather few national well organized and documented programmes. In most European countries, cervical cancer screening started as an opportunistic activity, performed on the initiative of women or doctors. This opportunistic screening activity is still predominant in most European countries.

The European Union has recommended cervical cancer screening since the start of the Europe against Cancer programme in 1987. European guidelines for quality assurance in cervical cancer screening were issued in 1993 (Coleman *et al.*, 1993). A Council recommendation in 2003 stressed the need for the adoption of organized screening programmes with personal invitations and quality assurance (Boyle *et al.*, 2003; European Commission, 2003).

Table 46 lists European countries that have organized screening programmes. Nationwide programmes with personal invitation started in the 1960s and 1970s in Iceland, Finland,

Sweden, Denmark and Latvia. However, participation in the Latvian programme decreased after 1987. In the United Kingdom, a computerized call/recall system was established in 1988. This is a system that invites women who are registered with a GP, keeps track of any follow-up investigation and, if all is well, recalls the woman for screening in three or five years time. National coordination and quality assurance was adopted in 1995. In the Netherlands, local programmes existed from the 1970s and a national organized programme was set up in 1996. A national programme started in Norway in 1995. A programme for the Flemish Region of Belgium including about 60% of the national population started in 1994. In Italy, a few local programmes started in the late 1980s or early 1990s, and national guidelines recommended organized programmes on a regional basis in 1996. In 2002, 12 regions out of 20 had programmes targeting in total about half of Italian women. Nationwide programmes were very recently started in Hungary and Slovenia. In the other countries listed, organized programmes are mainly pilot programmes and cover a small percentage of the national population. In Germany, a committee is currently considering the possibilities for establishing organized screening.

Screening test

Cytological (Pap smear) testing is generally used. A combination Ayre's spatula and brush or an extended-tip spatula is commonly used for sampling, although in Germany most smears are reported to be taken with a cotton-swab (Schenk & von Karsa, 2000). In Germany, a gynaecological examination is also a mandatory part of screening, while colposcopy is left to the discretion of the physician (Schenk & von Karsa, 2000). Colposcopy, although not recommended, is still

quite common in opportunistic screening in Italy (Segnan *et al.*, 2000).

Most smears are fixed on glass by the smear-taker. However, in the United Kingdom (National Institute for Clinical Excellence, 2003) and Denmark (Hoelund, 2003; Patologiafdelingen, Hvidovre Hospital, 2003), the screening programmes are changing to liquid-based cytology. The smears are read by cytotechnicians. In Finland, a trial of the use of neural-network-assisted screening (Papnet) is in progress (Nieminen *et al.*, 2003). Since 1999, the largest screening programme in Denmark has used automated reading (Focal Point; Patologiafdelingen, Hvidovre Hospital, 2003). In Denmark, national guidelines have been issued on the use of HPV testing in assessment of women with atypical cytological results (Kjær *et al.*, 2002a). Trials on the use of HPV testing for primary screening are under way in Finland (Nieminen *et al.*, 2003), Italy (Ronco *et al.*, 2004), the Netherlands (Bulkman *et al.*, 2004), Sweden (Dillner, 2000) and the United Kingdom (Cuzick *et al.*, 2003).

Screening interval and age

European guidelines (European Commission, 2003) recommend three- to five-year screening intervals, depending on the resources available, but there is wide variation in actual recommendations at the national level across Europe. The most commonly recommended interval between normal cytological tests is three years (Table 47). Five-year intervals are recommended in Finland, Ireland and the Netherlands. A three- to five-year interval used to be recommended in the United Kingdom, but recently a three-year interval was recommended for women aged 25–49 and five years for women 50–64 years old. These recommendations were based on an audit of screening histories (Sasieni *et al.*, 2003). The recommended interval is

Table 46. Organized programmes in Europe

| Country | Population included in organized cervical screening | Start | References |
|-------------|---|---|---|
| Austria | Regional programme in Vorarlberg (120 000 women, 4% of Austrian women 20+) | 1970 | Breitenecker <i>et al.</i> (2000) |
| Belgium | Flemish Region (about 60% of Belgian population) | 1994 | Arbyn & Van Oyen (2000) |
| Denmark | Regional programmes Nationwide | 1962 first pilot. 1969 local programmes and opportunistic smears. 1996 nationwide programmes | Lynge (1984); Lynge <i>et al.</i> (1996) |
| Estonia | Pilot programme (Tallinn, Tartu, Narva), invitation only via media | 2003 | T. Aareleid (2003) (personal communication) |
| Finland | National programme | 1961 first pilot. 1970 nationwide. | Kauraniemi (1969), Timonen & Pyörälä (1977) |
| France | Pilot programmes in 4 departments: Bas-Rhin, Isère and Doubs (500 000 women) and Martinique | 1990 (Isère) 1991 (Martinique) 1993–94 (Bas-Rhin and Doubs) | Schaffer <i>et al.</i> (2000) |
| Greece | Pilot programmes in Ormylia (< 20 000 women) and Ilia and Messinia Region | | Linos & Riza (2000) |
| Hungary | Nationwide | 2003 | Döbrössy & Bodo (personal communication) |
| Iceland | National programme | 1964 Reykjavik 1969 nationwide | Johannesson <i>et al.</i> (1982) (1982) |
| Ireland | Pilot programme in Mid Western Health Board Region (67 000 women) | 2000 | O'Neill (2000) |
| Italy | Regional programmes in 12 of 20 regions targeting 52% of women aged 25–64 | Most after 1996 (where 13% of population targeted). | Segnan <i>et al.</i> (2000); Ronco <i>et al.</i> (2003a) |
| Latvia | National programme | 1972. After 1987 the programme gradually disappeared due to economic and political factors | V. Grjunberg (personal communication) |
| Netherlands | Regional programmes Nationwide with national co-ordination and policy | 1970 local programmes and opportunistic screening 1996 national programme | Van Ballegooijen & Hermens (2000) |
| Norway | National programme National coordination and policy | 1959 first pilot 1980s - 1990s many opportunistic smears 1995 national programme | Messelt & Höeg (1967); Nygård <i>et al.</i> (2002) |
| Portugal | Regional programme in central Portugal (300 000 women) | 1990 | Real <i>et al.</i> (2000) |

Table 46 (contd)

| Country | Population included in organized cervical screening | Start | References |
|----------------|--|---|--|
| Romania | Regional Cluji county (200 000 women, 3% of Romanian women 25–64) | 2002 | Suteu <i>et al.</i> (2003) |
| Slovenia | Nationwide | 2003 | Primic Zakelj (personal communication) |
| Spain | Regional programme in Castilla y Leon | 1986 | Fernandez Calvo <i>et al.</i> (2000) |
| Sweden | Regional programmes Nationwide | 1964 first country 1965 national plan 1973 nationwide (except one city) | Ahlgren <i>et al.</i> (1969), Pettersson <i>et al.</i> (1986) |
| United Kingdom | Regional programmes Nationwide with national co-ordination and policy | 1988 computerized call/recal 1995 national co-ordination and quality assurance | Patnick (2000) |

one year in Germany, Austria and Luxembourg.

The European guidelines recommend screening for cervical abnormalities "starting at the latest by the age of 30 and definitely not before the age of 20" (European Commission, 2003). In the updated European Code against Cancer, this has been phrased as "Women from 25 years of age should participate in cervical cancer screening" (Boyle *et al.*, 2003). However, wide variation is also seen here in what is recommended at the national level. Most European countries recommend screening from age 25 up to age 64 or 65. The organized programmes in Finland and the Netherlands target women aged 30 to 60 years. In Germany and Austria, women aged 20 or older are eligible for annual cytology, and in Luxembourg those aged 15 or older are eligible.

The combination of differences in the recommended age group and in screening interval results in dramatic differences in the number of recommended lifetime smears, from 6–8 in Finland, Ireland and the Netherlands, 12–18 in most European countries, up

to 50 or more in Austria, Germany and Luxembourg.

Invitations

A call/recall system based on personal invitations is considered to be a key element of an organized programme in Europe. For this purpose, an accurate list of the target population with names and addresses is needed. Sources of such lists vary between countries and include population registries, health service registers, general practitioners' (GPs) medical files, electoral registers and others.

Usually, only women who are not registered as having had a cytological test within the recommended interval are invited. This 'integrated' approach is applied with the intention of saving resources by avoiding re-screening of recently tested women (Coleman *et al.*, 1993). It requires comprehensive registration of cytological testing, including opportunistic tests, at the population level. In some Italian programmes, all women are invited independently of their screening history (Ronco *et al.*, 1998). This approach may be used if cytology registration is

incomplete or if it is hoped to modify the spontaneous frequency of screening. In Finland, the organized programme invites all women (Nieminen *et al.*, 1999); until the 1990s, all smears from the organized programme were analysed in laboratories run by the Cancer Society of Finland (Nieminen *et al.*, 2002).

The nature of the invitation may vary from a suggestion to contact a smear-taker to a pre-assignment of a modifiable place and date. In randomized trials (Wilson & Leeming, 1987; Pierce *et al.*, 1989; Segnan *et al.*, 1998), compliance rates were significantly higher with letters offering pre-allocated appointments than with open-ended invitations.

Outside organized programmes, no systematic active personal invitation is sent. In Germany until 1995, statutory insurers used to issue yearly vouchers for reimbursement to all eligible women, which also served as a reminder.

Information campaigns via mass media are implemented both in areas covered by invitational programmes and in areas not covered.

Table 47. National recommendations in Europe on age group and screening interval

| Country | Age group | Interval between normal tests (years) | Lifetime number of recommended smears | References |
|----------------|---|---|---------------------------------------|---|
| Austria | 20+ | 1 | 50 (to age 70) | Breitenecker <i>et al.</i> (2000) |
| Belgium | 25–64 | 3 | 14 | Arbyn & Van Oyen (2000) |
| Denmark | 23–59 | 3 | 13 | Sundhedsstyrelsen (1986) |
| Finland | 30–60 | 5 | 6 | Anttila & Nieminen (2000) |
| France | 25–65 | 3 | 14 | Schaffer <i>et al.</i> (2000) |
| Germany | 20+ | 1 | 50 (to age 70) | Schenk & von Karsa (2000) |
| Greece | 25–64 (in pilot) | 3 after 2 negative smears (Omylia), 2 (Iliia/Messinia) | 15 (Omylia) 21 (Iliia/Messinia) | Riza <i>et al.</i> (2000) |
| Hungary | 25–65 (previously 18+) | 3 after 2 negative smears (from 2003, before 1) | 15 | Döbrössy & Bodo, (personal communication) |
| Iceland | 25–59 (1964–69) 25–69 (1970–87) 20–69 (1988–) | 2–3 | 18–26 | Sigurdsson (1999) |
| Ireland | 25–60 (in pilot) | 5 | 8 | O’Neill (2000) |
| Italy | 25–64 | 3 | 14 | Segnan <i>et al.</i> (2000) |
| Luxembourg | 15+ | 1 | 55 (to age 70) | Scheiden <i>et al.</i> (2000) |
| Netherlands | 30–60 (35–53 until 1996) | 5 (3 until 1996) | 6 | Van Ballegooijen & Hermens (2000) |
| Norway | 25–69 | 3 | 15 | Nygård <i>et al.</i> (2002) |
| Portugal | 20–64 | 3 after 2 negative smears | 17 | Real <i>et al.</i> (2000) |
| Romania | 25–65 | 3 | 14 | Suteu <i>et al.</i> (2003) |
| Slovenia | 20–64 (formerly 20+) | 3 after 2 negative smears (from 2003, before 1) | 17 | Primic Zakelj (personal communication) |
| Spain | 35–64, below 35 if with risk factors. Most regions women aged 25–65 | 5 after 2 negative smears, but 3 in organized programme | 14 (age 25–65, 3 year) | Ascunze Elizaga <i>et al.</i> (1993); AETS (2002); Fernandez Calvo <i>et al.</i> (2000) |
| Sweden | 30–49 (1965–85) 20–59 (1985–) | 4–5 (1965–85) 3 (1985–) | 14 | Mählck <i>et al.</i> (1994), Dillner (2000) |
| United Kingdom | 20 (or 25 from 2004)–64 | 3 for age 25–49 5 for age 50–64 (From 2004, before 3–5) | 12 | Patnick (2000) NHS (2003a) |

GPs frequently act as advisers both in the presence and in the absence of personal invitations. Attendance following invitation was higher with letters signed by the GP than with letters signed by programme staff (Segnan *et al.*, 1998; Palm *et al.*, 1993). In the United Kingdom, GPs are paid for screening based on the coverage among their patients. This was introduced to increase coverage (Rudiman *et al.*, 1995).

The facilities for testing and the professionals involved vary widely between countries and between organized and opportunistic activity (Table 48). In the Netherlands and the United Kingdom, smears are most commonly taken by GPs or their assistants, while gynaecologists play a major role in most other countries, especially in opportunistic screening. In the Finnish organized programme, the smears were taken at maternity and child health centres invariably by public health nurses and midwives. In the Italian organized programmes, smears are most often taken by midwives in family-planning clinics, and midwives also participate in Finland and Sweden.

Coverage and participation

Table 49 shows published estimates of participation by cervical screening at the national level. This measure has been provided at a national level only in Finland, Iceland, Norway, England and the Netherlands. For France, an estimate has been made on the basis of individual linkage on a sample of women, using insurance data. For a number of other countries, estimates are based on interviews, with the possibility of recall bias, although some kind of validation was frequently performed. Comparability of the findings is also limited by differences in the age groups considered, and by the fact that hysterectomized women were excluded in some case (e.g., England) but not in others (frequently not mentioned).

Participation over 80% is seen in England and Iceland and in rural areas of Sweden and Denmark. Participation of 70–80% is found in the Flemish part of Belgium, Finland, the Netherlands, Norway and Copenhagen, Denmark. Participation is around or below 60% in Austria, France, Italy and Spain. In Germany, where women are eligible for yearly screening, the number of tests in 1996 was about 50% of the number of women (Schenck & von Karsa, 2000). A three-year participation of 65% was estimated for the European Union (women aged 25–54 years) on the basis of an interview survey in 1991 (Coleman *et al.*, 1993).

Participation also varies between areas within countries. This variation was quite low in England, with participation ranging from 76% in London to 85% in the East Midlands in 2002–03 (NHS, 2003a). However, in Spain, the reported participation (women 40–70 years) ranged from 25% in Castilla-La Mancha to 61% in Madrid (AETS, 2002). In Italy, there was a strong gradient in participation from northern-central (53–61%) to southern Italy (26%) (Ronco *et al.*, 2003a; Mancini *et al.*, 2004). In France, the annual number of tests ranged from 17 to 39 per 100 women, with a north–south and west–east increasing trend (Rousseau *et al.*, 2002).

There is also a difference in activity by age, with a common pattern of lower activity at the highest ages. In England in 2002–03, participation was over 80% among women aged 30–59 years, 74% among those aged 25–29, and 77% among those aged 60–64 (NHS, 2003a). In Spain, participation decreased from 61% in the 40–45-year age group to 31% in the 61–65-year age group (AETS, 2002). In Flanders (Belgium), participation remained high up to 40 years of age, and decreased thereafter (Arbyn *et al.*, 1997). In Italy, it was 27% at age 25–34, over 50% at age 35–44, and 43% at age 55–64

(Mancini *et al.*, 2004). In France, the rate of activity increased slightly up to age 50–54, and then decreased rapidly (Rousseau *et al.*, 2002).

In England, the introduction of the computerized call/recall system in 1988 and the target payments for GPs in 1990 increased the five-year participation for women aged 25–64 years from 40% in 1988 (Havelock *et al.*, 1988; Shroff *et al.*, 1988; Robertson *et al.*, 1989b) to persistently over 80% between 1992 and 2003 (NHS, 2003b). In Norway, opportunistic screening has been very common, but when organized screening with personal invitations was introduced in 1995 the participation increased from 65% to 71% (Nygård *et al.* 2002). In France, a three-year participation of 69% was found in the organized programme of Bas-Rhin after four years of activity (Fender *et al.*, 2000), compared with the national estimate of 54% (Rousseau *et al.*, 2002). In Castilla y Leon, a region of Spain with an organized programme, the estimated three-year participation of 41% was similar to the 44% for Spain (AETS, 2002). In Italy, national participation data for 1999–2000 were only marginally influenced by the recently started organized programmes, although in one of the latter, the three-year participation was estimated to be 74%, compared with 43% before (Ronco *et al.*, 1997). A strong reduction in variability by age, education and marital status was also observed.

Excess use of Pap testing

Pap testing is unevenly distributed among women in many countries, with many women not screened at all or not screened within the recommended interval, and other women screened more frequently than recommended.

In general, over-testing is assumed to be high in opportunistic screening. The level of testing is high in Germany, where women are eligible for yearly

Table 48. Staff involved in taking smears and methods of communicating results in European countries

| Country | Smear-taker | Communication of cytology results | |
|-------------|--|---|--|
| | | Normal | Suspicious |
| Austria | Gynaecologists | Mail or phone to the smear taker | Mail or phone to the smear taker |
| Belgium | Gynaecologists/GPs | Report to the smear taker | Report to the smear taker |
| Denmark | GPs | Mostly: woman asked to call GP | As for normal or GP contact woman |
| England | GPs or general practice nurses | Report to the smear taker | Report to the smear taker |
| Finland | Midwives or public health nurses | Letter to woman | Phone and always by letter with fixed appointment |
| France | Gynaecologists/GPs | Not specified | Not specified |
| Germany | Office-based gynaecologists (90%) and GPs (10%) | By the smear taker | Mail or phone by the smear taker |
| Greece | <i>Organized:</i> Gynaecologists (Ormylia) gynaecologists, trained rural doctors and midwives (Iliia/Messinia) <i>Opportunistic:</i> gynaecologists (Riza <i>et al.</i> , 2000) | <i>Organized:</i> letter directly to the women | <i>Organized:</i> phone or personal meeting with screening physician or house call |
| Iceland | Gynaecologists/GPs (Sigurdsson <i>et al.</i> , 1991) | Not specified | Not specified |
| Ireland | GPs, family planning and community clinics, hospitals | Letter to woman | Advised to contact smear taker |
| Italy | <i>Organized:</i> mainly midwives in family planning clinics <i>Opportunistic:</i> mainly gynaecologists | <i>Organized:</i> mostly letter directly to the woman | <i>Organized:</i> letter or phone call to woman |
| Luxembourg | GPs and/or gynaecologists | Not specified | Not specified |
| Netherlands | GPs and their practice assistants | Via the GP | Via the GP |
| Norway | Primary physicians (Krogh & Malterud, 1995) | Not specified | Not specified |
| Portugal | GPs (organized) | <i>Organized:</i> letter via the GP | <i>Organized:</i> letter via the GP |
| Spain | <i>Organized:</i> family doctors <i>Opportunistic:</i> mainly gynaecologists (>80%) and family clinics of primary care centres (about 20%) (AETS, 2000) | Organized: letter via the primary care physician | <i>Organized:</i> by the primary care physician |
| Sweden | Nurse-midwives (Sarkadi <i>et al.</i> , 2004) | Letter to woman | Referral to gynaecological out-patient clinic for test result |

Modified from Linos & Riza (2000)

Table 49. Participation estimates at the national level in European countries

| Country | Estimated coverage ^a | Source | Reference |
|-------------|--|---|--|
| Austria | Lifetime: 60% 2+ smears 10% 1 smear 30% never | Interviews with sample of women | Vutuc <i>et al.</i> (1999) (reported in Breitenecker <i>et al.</i> , 2000) |
| Belgium | 74% in 3 years, Flemish region, 64% in 3 years, Walloon region | National health interview survey | Arbyn & Van Oyen (2000) |
| Denmark | 85% County of Funen 73% Copenhagen | Register linkage | Hoelund (2003); Patologiafdelingen, Hvidovre Hospital (2003) |
| England | 81% in 5 years, 71% in 3 years, 2003 | Register linkage | NHS (2003b) |
| Finland | 70% (organized screening) 93% (all smears) | Register-based national health interview survey | Finnish Cancer Registry (2003) |
| France | 54% in 3 years, 1998–2000 | Registration of smears in two health insurance systems and linkage for sample of 9374 women | Rousseau <i>et al.</i> (2002) |
| Germany | 42–47% in 1997 for women aged 25–54 | Personal interviews | Kahl <i>et al.</i> (1999) |
| Iceland | 83% in 1990–92 | Register linkage | Sigurdsson (1999) |
| Italy | 50% reporting usual frequency of 3 years, 1999–2000 | National periodic survey on health (44 433 women) | Mancini <i>et al.</i> (2004) |
| Netherlands | About 80% in 2 years, 1996–97 | Register linkage | Van Ballegooijen & Hermens (2000) |
| Norway | 71% in 1998–2000 | Register linkage | Nygård <i>et al.</i> (2002) |
| Spain | 44% reporting one or more tests in 3 years for preventive reasons | Personal interview. random sample (2409 women) | AETS (2002) |
| Sweden | >80% northern Sweden, 20–30% Malmö, 50–70% most common | Register linkage | Dillner (2000) |

^a Proportion of the target population having had at least one test in the defined interval

screening; the number of smears in 1996 was about 50% of the number of women in the target population. In Italy, 52% of screened women reported having a test every year (Mancini *et al.*, 2004).

Over-testing in countries and regions with organized screening programmes depends on the organization of the programme. The total level is

often high in countries where the organized programme runs independently of opportunistic activity. In Finland, 200 000 smears are taken annually within the organized programme and 400 000 smears are taken outside (Finnish Cancer Registry, 2003). In an Italian programme in which all women are invited independently of previous testing, 20–25% of those who joined

the programme also had tests outside the protocol (Ronco *et al.*, 1997). Sweden, where there were regional differences in the organizational set-up, over-testing was heavy in 1994, with 292 000 smears taken in the organized programme and 656 000 taken outside. Opportunistic testing was free, whereas a small fee had to be paid for the organized screening (Dillner,

2000). Since a government report examined this issue (Socialstyrelsen, 1998), all counties have changed to the 'integrated approach' (see above) for invitations.

There can be a lower level of over-testing in integrated programmes, although this is not always the case. In England, GPs are paid based on coverage of their patients and not on the number of smears taken. Data on over-testing are not published, but the level seems to be small. In 2002–03, a total of 4.1 million smears were taken. There were 13.8 million women in the target 25–64-year age group, of whom 66.1% were screened within the last three years, giving 3.0 million annual smears used for screening. An additional 1.0 million women were recalled more often than every third year for surveillance etc. This leaves very few smears corresponding to possible 'over-use' (NHS, 2003b). In Norway, the average number of smears per woman aged 25–69 in a three-year period decreased from 1.68 to 1.52 when an integrated programme was introduced, at the same time increasing participation (Nygård *et al.*, 2002). Denmark runs integrated programmes, and the level of over-testing was 28% in Copenhagen in 1999–2001 (Patologifdelingen, Hvidovre Hospital, 2003), but only 4% in Fyn in 1999 (Hoelund, 2003). In the Netherlands, out of about one million smears taken in 1996, 450 000 were in the organized programme, 300 000 were other 'primary' smears, and 250 000 'secondary' (follow-up or repeat) smears (van Ballegooijen & Hermens, 2000). In Bas-Rhin, France, 63% of women had a second test before the recommended interval (Fender *et al.*, 2000).

The difficulties in limiting over-testing are illustrated by the fact that 27–29% of female primary physicians in Norway in 1995 recommended screening more often than the three years stated in the national guidelines

(Krohg & Malterud 1995). In Stockholm, a common practice among private gynaecologists seems to be to have an annual appointment with private patients and a Pap test is often part of the consultation (Sarkadi *et al.*, 2004).

Cytological interpretation and management of abnormal results

There is no unique European system of classification. National classification systems are applied in the Netherlands and in the United Kingdom. In Germany (where standardized national reporting forms exist) and in Austria, the Munich classification is used (Schenk & von Karsa, 2000; Breitenecker *et al.*, 2000). In Italy, the Bethesda system is widely applied, although with many local adaptations (Ronco *et al.*, 1998). A standard reporting protocol, related to the Bethesda system, is applied in the Flemish Region of Belgium (Arbyn & Van Oyen, 2000). Tables of 'equivalent terminology' between different classifications have been published in the European Guidelines (Coleman *et al.*, 1993). Data on comparability of the criteria actually used in different countries are limited. In a study of agreement in cytological interpretation conducted in six Italian laboratories and one Danish using the Bethesda 1991 classification, agreement between the Danish and the Italian results was similar to that within Italians (Ronco *et al.*, 2003b).

Table 48 summarizes the methods of communication of test results to the woman. In some cases the report is sent directly to the woman (e.g., Italian organized programmes), while more frequently the laboratory reports to the smear-taker. The practice of sending negative test results directly to the women was abandoned in one Danish county after a survey showed that women preferred to have the results reported via their GP (Andreasen *et al.*, 1998). In most countries, the deci-

sion on the action to be taken following a non-negative smear is left to the smear-taker (Belgium, Germany), while in others (England) the recommendation is given by the laboratory and it is the responsibility of the smear-taker to ensure that the woman receives the result.

Criteria for management of women based on cytology results vary widely, also depending on the cost and availability of colposcopy facilities. National guidelines with implementation policies are applied in England and the Netherlands. National guidelines for the management of abnormal smears exist in France (ANAES, 1998), Austria (stated in Breitenecker *et al.*, 2000) and Germany (Bundesärztekammer, 1994; Schenk & von Karsa, 2000). In Italy the national guidelines recommend development of detailed local protocols for the management of abnormal results (Ronco *et al.*, 1998). Recommendations have also been prepared in the Flemish programme (Arbyn & Van Oyen, 2000).

In the United Kingdom, women with moderate and severe dyskaryosis (equivalent to HSIL in the Bethesda system) are referred for colposcopy, while those with mild dyskaryosis (Bethesda: LSIL) and borderline cytology (Bethesda: ASCUS) are advised to repeat testing and referred for colposcopy only in case of persistence, although some of these cases are in fact directly referred for colposcopy. The same policy is applied in Belgium and the Netherlands. In France, a choice between colposcopy and repeat cytology is left for borderline and low-grade lesions. In Portugal, women with ASCUS are advised to undergo repeat testing, while those with LSIL or worse are referred for colposcopy. In Italy, most organized programmes refer all women with ASCUS or more severe cytology for colposcopy, although some programmes perform a repeat cytology in the case

of ASCUS (but not LSIL). Referral of all ASCUS-positive women for colposcopy is also the usual practice in opportunistic activity in Italy. In Finland, treatment is given to women with low-grade dysplasia, whereas in Norway a more conservative stance is taken and treatment is given only after three repeated low-grade abnormal results (Nygård *et al.* 2002). In Denmark, follow-up of women with atypia varies from direct referral to colposcopy to a repeat test within 6–12 months (Biggaard *et al.*, 2000).

An issue relevant to screening effectiveness is that all women needing further action (repeat or colposcopy) should actually have it. Fail-safe methods are implemented in most organized programmes. Monitoring of follow-up is applied in French organized programmes (Schaffer *et al.*, 2000). In the Netherlands, it is the responsibility of the GP to inform the woman of the results and to ensure completion of follow-up. It has been planned that laboratories should provide GPs with lists of women with incomplete follow-up (van Ballegooijen & Hermens, 2000). A similar system is implemented in Denmark (Patologi-afdelingen, Hvidovre Hospital, 2003). In Finland and in most Italian organized programmes, women needing colposcopy receive a pre-arranged appointment to a reference centre and are reminded in case of default.

Quality assurance

Several factors contribute to the impact of cervical screening, including coverage of the targeted population, the actual participation, the quality of smear-taking and interpretation, the follow-up of women with abnormal results, the quality of diagnostic procedures and initial treatment. Several initiatives have been taken to develop and promote quality assurance systems, and guidelines have been published both at European and national levels.

Quality assurance addresses the following issues: rules concerning structural requirements (e.g., number of smears interpreted, qualification and training of staff), procedures to be followed (e.g., methods of smear preparation, re-interpretation of smears, including guidelines for the management of women); and monitoring of performance for taking action in response to such information.

National guidelines concerning cytological interpretation exist in Austria (reported in Breitenecker *et al.*, 2000), England (Johnson & Patnick, 2000), France (Marsan & Cochand-Priollet, 1993), Germany (Bundesärztekammer, 1994; reported in Schenk & von Karsa, 2000) and the Netherlands (van Ballegooijen & Hermens, 2000). Guidelines for quality assurance in colposcopy were published for England (Luesley, 1996) and the Netherlands (Helmerhorst & Wijnen, 1998). Poor compliance with guidelines in Austria has been reported (Breitenecker *et al.*, 2000).

Rules or guidelines concerning the number of smears to be read exist in many countries both as a maximum number per cytologist (Austria, England, Germany, the Netherlands) and as a minimum (Denmark, England, Italy). Laboratories vary greatly in size and in some countries many are small. In the Flemish Region of Belgium, a total of 620 000 smears were processed in 1993 in over 100 laboratories (Arbyn & van Oyen, 2000). In Austria, the annual number of smears per laboratory varied from 3000 to 150 000, with an average of 25 000 (Breitenecker *et al.*, 2000). In Germany, an annual total of 17 000 000 smears are interpreted by some 2000 laboratories (Schenk & von Karsa, 2000). In the Netherlands, the annual number varies from 5000 to over 50 000 per laboratory (van Ballegooijen & Hermens, 2000). Among Italian laboratories involved in organized programmes in 1997, the

workload varied from 3000 to over 50 000 smears per year (Ronco *et al.*, 1998).

Proficiency testing for cytological interpretation is compulsory for all laboratory staff in the United Kingdom, and for cytopathologists (but not for cytotechnicians) in Germany. In many other countries, proficiency testing is encouraged but not compulsory.

Re-screening of a sample of negative smears, which is mandatory in the USA, is not compulsory in most European countries. A rapid review (Faraker & Boxer, 1996) of all negative smears is mandatory in England (NHSCSP, 2000) and this policy is supported by a meta-analysis (Arbyn & Schenk, 2000). Suspicious smears are usually reviewed by a supervisor. In Italy, where quality assurance programmes are decided on a regional basis, circulation and discussion of sets of smears is becoming widely applied on both a local and national basis in order to improve consistency between laboratories (Branca *et al.*, 1998; Ronco *et al.*, 2003b).

Data registration

Monitoring of screening performance requires comprehensive registration of all events related to screening and the recovery and linkage of the data at an individual level in order to allow reconstruction of the screening histories and their results. European guidelines (Coleman *et al.*, 1993) recommend comprehensive registration of all cytological and histological findings.

Registration of events related to screening, particularly cytological results, exists in the organized programmes listed in Table 46 and in other areas. Individual linkage of data takes place in Denmark, Finland, Iceland, the Netherlands, Norway, Sweden, the United Kingdom, and in the organized programmes in Italy. In Germany, individual linkage is prohibited due to regulations on privacy.

Where results are registered, the level of comprehensiveness varies. Comprehensive computerized registration of all tests is performed in the Netherlands through a national database covering all pathology units (the PALGA system). In the United Kingdom, registration of cytology is comprehensive (data are registered locally and forwarded periodically for central analysis) and highly complete, leaving out only a small percentage of privately performed tests.

Screening registers with comprehensive registration of cytology have also been set up in the French organized programmes through agreements with the involved parties (laboratories, GPs, gynaecologists) and in the Flemish Region in Belgium. In the latter case, personal identification codes are encrypted. In other areas, however, complete registration only of cytology and histology taken within the organized programme is possible, while registration of opportunistic test results and of histology performed outside the reference centres is incomplete or absent. This is the case for some Italian programmes, where completeness also depends on the number of laboratories in the area and on the amount of private activity.

In France, outside organized programmes, computerized registration of cytological testing is performed at the national level by the social security system, although mainly for administrative purposes. Individual linkage has been performed experimentally on a sample of women in order to estimate participation (Rousseau *et al.*, 2002). In Germany, cytology reports are registered on paper, transmitted to regional insurance billing offices, and finally registered on a central computerized database. Only results of initially abnormal test results and of a random sample of normal ones are registered. Follow-up and histology data after an initially abnormal result are reported

on the same sheet. However, problems of quality and completeness have been reported. No special registration of colposcopies or biopsies exists (Schenk & von Karsa, 2000). Colposcopies performed in referral centres are recorded by most Italian programmes and partially in England.

Performance indicators

The European Guidelines proposed a number of standard tabulations and parameters (coverage, interval to reporting, proportion of unsatisfactory smears, treatment compliance, sensitivity and specificity, distribution of invasive cancers, interval cancers) for 'short-term monitoring' of programmes (Coleman *et al.*, 1993). In England, a national system of measurements and of reference standards for them, each related to an objective, was adopted (NHSCSP, 1996). Annual reports, produced in both a synthetic (NHS, 2003b) and detailed (NHS, 2003a) format, are available on the NHS screening web site (<http://www.cancerscreening.nhs.uk>). In Italy, a system of process indicators (partly with reference standards) has been published (Ronco *et al.*, 1999) and included in official guidelines. Annual surveys of the activity of organized screening programmes have been conducted from 1998 and a report published annually from 2002 (Ronco *et al.*, 2002). In the Netherlands, regular reports are produced on the outcome of the organized programme. Regular reports have been published from the Icelandic (Sigurdsson, 1995), Norwegian (Nygård *et al.*, 2002) and Finnish (Finnish Cancer Registry, 2003) programmes. Process measures have been published for French organized programmes (Fender *et al.*, 2000; Schaffer *et al.*, 2000) and the distribution of cytology results for the Flemish Region has been reported (Arbyn & van Oyen, 2000).

Participation is a key indicator and has been described in a previous section. Another important indicator is the proportion of unsatisfactory cytological tests. The proportion is high in England, at 9.4% of smears (NHS, 2003b), plausibly as a result of strict criteria for adequacy. In Norway, 4.7% of smears were considered unsatisfactory in 1998–2000 (Nygård *et al.*, 2002). The Netherlands has 1% (van Ballegooijen & Hermens, 2000), Finland 0.004% (Finnish Cancer Registry, 2003), Flemish programmes 0.6–1.0% (Arbyn & van Oyen, 2000), the French programmes 0.12–2% (Schaffer *et al.*, 2000) and the Italian organized programmes 3.8% (Ronco *et al.*, 2003a). In Copenhagen in 1999–2001, 2.5% of smears were unsatisfactory, but 8.5% were normal without endocervical cells. In the latter case, the GP decides whether testing should be repeated (Patologifdelingen, Hvidovre Hospital, 2003). In Funen in 1999, 7.5% of smears were unsatisfactory, including smears without endocervical cells. This percentage decreased to 2.5% after introduction of liquid-based cytology (Hoelund, 2003). In many organized programmes, reports on unsatisfactory smears are sent to smear-takers.

A measure of the proportion of women referred for further action (repeat cytology or colposcopy) is obviously useful as an indication of the human and economic cost of screening. More frequently, the proportion of abnormal cytological results (or of screened women with abnormal results) is reported. However, this does not translate immediately to referral or repeat action, both because guidelines leave choice for some diagnoses (e.g., LSIL/ASCUS in France) and because of referral for clinical reasons. Cyto-histological correlation data are frequently reported, sometimes in terms of positive predictive value. However, comparison is difficult because of the

variability of criteria for inclusion, both in relation to the cytological diagnoses considered (frequently only certain cytological categories among those of referred women are included) and to the presence of histology (in some cases but not others, women examined colposcopically but without histology are included, assuming that no biopsy was done because no suspect area was identified at colposcopy). It is nevertheless clear that the proportion of screened women immediately referred for colposcopy varies between countries from 0.8% in Finland (Finnish Cancer Registry, 2003) to 2.9% in Italian organized programmes (Ronco *et al.*, 2003a).

Some measure of completeness of follow-up is also reported or can be computed from available data, although sometimes the data relate to colposcopy only (Italy) and sometimes to either colposcopy or repeat testing (France). Statistics on the time between referral and attendance for colposcopy are computed in England.

United States and Canada

The type of organization of cervical cancer screening services in the USA and Canada covers the range from opportunistic screening, with access based on availability of individual or third-party financial resources, to organized screening at the local, regional and national level funded by work-based groups or government agencies.

Organization and financing

United States

In the USA, cervical cancer screening is provided in various settings: private practices, public health clinics, community health centres, sexually transmitted disease clinics, family planning clinics and prenatal clinics. This screening is offered on an entirely opportunistic basis. Financing for cervical cancer screening and other

preventive services depends on a woman's personal resources and/or health insurance coverage. Most insurance plans cover cervical cancer screening services, but if follow-up testing is necessary, there may be cover only for part of the expenses.

In the Government-sponsored Medicare and Medicaid, the proportions paid by individuals, if any, are limited by law and are often related to income levels. Medicare provides reimbursement for screening services of individuals aged 65 years or more and some younger disabled individuals. Medicaid, administered by states, provides reimbursement for very low-income families with highly limited resources. Persons covered by some type of insurance, public or private, represent a median of 84% of the state populations (Mansley *et al.*, 2002) and there is some geographical variation in the availability of insurance. For example, the State of Wisconsin has coverage for 91% of its constituents whereas the State of Texas has coverage for only 76% of its residents (Mansley *et al.*, 2002). Populations with lower socioeconomic status are more likely to have no or insufficient insurance coverage (Henson *et al.*, 1996).

Special programmes like the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), administered by the Centers for Disease Control and Prevention (CDC), make cancer screening services available to uninsured or underinsured women who meet certain income and family size criteria but are not eligible for other government reimbursement programmes. Funding is available to provide screening and certain follow-up services for only 6% of women eligible for this programme, aged 18–64 years. In the absence of a structured national health care registration system, women are informed about and recruited into the NBC-

CEDP by a variety of means including the media, community- and religion-based organizational health fairs and public health announcements. However, the first contact with the programme is initiated voluntarily by the woman when she applies for eligibility. Since 2001, many professional organizations and government agencies (CDC, the Institute of Medicine–US Preventive Services Task Force (USPSTF) and the National Institutes of Health (NIH)) have deliberated on the features of cervical cancer screening in the USA (see Table 50). After extensive review of published evidence and consensus building among the various groups, updated recommendations have been published for cytological testing and follow-up of women with abnormal results. New screening recommendations include changes in the age to begin screening (previously 18 years, now 21), frequency of repeat screening if results are negative (previously annual, now up to every three years if over age 30), and the age to consider ending screening (previously no recommendation, now age 70 if recent screening results are negative) (Saslow *et al.*, 2002; American College of Obstetricians and Gynecologists, 2003; US Preventive Services Task Force, 2003).

Canada

In Canada, organization and provision of health care is the responsibility of the provincial and territorial governments. The universal coverage includes cancer screening and follow-up activities. Furthermore, most provinces have cancer agencies that are usually responsible for planning, coordinating and monitoring cancer screening programmes.

Since the introduction of cytological testing in Canada, opportunistic cervical cancer screening has been the most frequently used method to screen women. In recognition of the fact that

Table 50. Recommendations for cervical cancer screening, United States, 2003

| Organization | American Cancer Society (ACS), Nov./Dec. 2002 (Saslow <i>et al.</i> , 2002) | American College of Obstetricians and Gynecologists (ACOG), Aug. 2003 (American College of Obstetricians and Gynecologists, 2003) | US Preventive Task Force (USPSTF), Jan. 2003 (US Preventive Services Task Force, 2003) |
|----------------------------------|---|--|---|
| When to start cervical screening | Age 21 or within 3 y of start of sexual activity | Age 21 or within 3 y of start of sexual activity | Age 21 or within 3 y of start of sexual activity |
| Interval | Annually with conventional or every 2 y using liquid-based cytology; age > 30, women with 3 negative may be screened every 2–3 y HPV-negative, Pap-negative: every 3 y | Every year for women < 30 or every 2–3 y for women ≥ 30 (except women with HIV, immunosuppressed or DES exposure) HPV-negative, Pap-negative: every 3 y | |
| Thin Prep | Recommend | Option | Insufficient evidence |
| HPV testing with ASCUS | | Option | Insufficient evidence |
| HPV testing > 30 | Guidelines not out before FDA approval; preliminary recommend | Option | Insufficient evidence |
| Post-hysterectomy | Discontinue if for benign reasons | Discontinue except in special circumstances | Discontinue |
| When to stop cervical screening | Age 70 or 3 or more negative tests within 10-year period | No upper limit | > 65 |

effective organization not only reduces the cost of screening programmes but improves their effectiveness, recommendations have been made on several occasions over the years for the development of organized screening programmes that incorporate a computerized information system, population-based recruitment and effective quality management.

Summarized below are highlights of the recommendations from the 1989 National Workshop on Cervical Cancer Screening (Miller *et al.*, 1991). These recommendations have been variably accepted and updated by provincial agencies responsible for screening.

- Cytological screening should start at age 18 years or at initiation of sexual activity.
- A second test should, in general, be performed after one year, especially for women who begin screening after age 20.
- If the first two tests are satisfactory and show no significant epithelial abnormality, women should, in general, be advised to be re-screened every three years up to age 69.
- Screening should occur at this frequency in areas where a population-based information system exists for identifying women and allowing notification and recall. In the absence of such a system, it is advisable to repeat tests annually.
- Women over the age of 69 who have had at least two satisfactory tests and no significant epithelial abnormality in the last nine years and who have never had biopsy-confirmed severe dysplasia or carcinoma *in situ* can leave the cervical cytology screening programme.
- If mild dysplasia is found, a cytological test is to be repeated every six months for two years.
- If the lesion persists or progresses to moderate or severe dysplasia, the patient must be referred for colposcopy.
- More frequent testing may be considered for women at high risk (first intercourse at less than 18 years of age, multiple sexual partners, partner who has had multiple sexual partners, smoking, low socioeconomic status).
- Women do not need to be screened if they have never had sexual intercourse or have had a

hysterectomy for a benign condition with adequate pathological documentation that the cervical epithelium has been totally removed and previous screening tests have been normal.

Two Canadian provinces, British Columbia and Nova Scotia, have well established, organized programmes for cervical cancer screening and in recent years other provinces such as Alberta, Manitoba, Ontario and Prince Edward Island have launched new programmes. These programmes target all women in the provincial population in a specified age range (usually 18–69 years), but no province yet has population-based recruitment. Variation between provinces in the implementation of screening programme components reflects the maturity of their programme development (Table 51) (Health Canada, 2002).

Most women who develop cervical cancer have either not been screened or have been screened too infrequently (Quality Management Working Group, 1998). About 60% of cervical cancers occur in women who have not been screened in the previous three years. Lack of organization has contributed to this failure, including an inability to reach high-risk women, inadequate quality control, or ineffective follow-up procedures.

The cost of cervical cancer screening and follow-up of abnormal findings is covered through universal provincial health funding.

Extent of use and access

United States

The extent of screening in the USA is affected by the proportion of women with some reimbursement for primary care and preventive health, and approximately 50 million cytological tests are performed annually (Kurman *et al.*, 1994). The NBCCEDP provides approximately 250 000 of those tests.

About 7% of all tests are reported to reveal an abnormality requiring further testing (Jones & Davey, 2000).

The Behavioral Risk Factor Surveillance System (BRFSS) and the National Health Interview Survey (NHIS), both administered by the CDC, show that more than 85% of women in the USA have had a previous cervical cancer screening test, and that approximately 80% have had one in the past two years (Blackman *et al.*, 1999).

Overall, screening tends to occur more frequently among younger women (every 1–2 years under age 40) than among older women (40 years or older), who present themselves for screening services less often as they have less need for reproductive health services. According to the NHIS 2000 data, over 82% women aged at least 25 years reported having a test within the last three years; the numbers are slightly different from those from the BRFSS because of the time interval included. The groups with the lowest proportions of women who had had a test within the previous three years were women without a usual source of health care (58.3%; 95% CI 55.3–61.3), women without health insurance (62.4%; 95% CI 58.1–66.8) and women who immigrated to the USA within the last 10 years (61.0%, 95% CI 55.2–66.8). Women with lower levels of education, women with limited income and women with chronic disabilities had lower levels of screening compared with other groups (Swan *et al.*, 2003).

The burden of cervical cancer remains highest among women who are rarely or never screened, who account for an estimated 60% of newly diagnosed invasive cancers (Sung, 2001).

Canada

In Canada, access to cervical cancer screening is available to all women who meet the criteria for screening either through national or provincial

programmes. Table 52 shows the frequency of self-reported cytological tests in Canada by province and age group for the period 1998–99.

More recently, the Canada Community Health Survey (CCHS), a national, biennial, cross-sectional survey, provided information on cervical cancer screening (Statistics Canada, 2002). From the survey cycle of 2000/2001, an estimated 89% of Canadian women aged 20–69 years answered "Yes" to the question "Have you ever had a Pap test?", with the highest percentage in the Atlantic Provinces (95%) and the lowest in Quebec (83%). Nationally, 53% and 73% of women aged 18–69 years reported having had a test within the last year and last three years, respectively, with the highest percentages in Nova Scotia (60% for one year; 80% for three years) and the lowest in Quebec (50% for one year and 67% for three years).

Methods of assuring quality

United States

In the 1980s, intensive media coverage of poor cytology laboratory practices and charges of lax enforcement of federal regulations contributed to the passage of the Clinical Laboratory Improvement Amendments (CLIA) in 1988 and the regulations that now define standards of cytology laboratory practice in the USA. CLIA and the related regulations serve as a baseline, through biennial inspections and certification, for assessing the quality of laboratory work including cervical cytology (Lawson *et al.*, 1997). The regulations allow for enforcement of CLIA standards and for corrective measures when laboratories fail to meet these standards. The Centers for Medicare and Medicaid Services (CMS) in the US Department of Health and Human Services and the CDC are responsible for establishing and implementing the CLIA regulations. CMS is responsible

Table 51. Organized screening programmes in Canadian provinces

| Province | Programme | Year of inception | Computerized information system ^a | Target age group | Screening frequency |
|-----------------------|-----------|-------------------|--|------------------|--|
| Newfoundland | No | – | ✓ | 18+ | Annual |
| Nova Scotia | Yes | 1991 | ✓ | 18+ | Annual |
| Prince Edward Island | Yes | 2001 | ✓ | 20–69 | After three normal annual tests, screening should be continued at least every 2 y |
| New Brunswick | No | – | – | – | – |
| Quebec | No | – | – | 18–69 | Annual |
| Ontario | Yes | 2000 | ✓ | 20–69 | After three normal annual tests, screening should be continued every 2 y |
| Manitoba | Yes | 1999 | ✓ | 18–69 | After three normal annual tests, screening should be continued every 2 y |
| Saskatchewan | No | – | – | – | – |
| Alberta | Yes | 2000 | Under development | 18–69 | Annual (to be reviewed when all components of programme in place) |
| British Columbia | Yes | 1960 | ✓ | 18–69 | After three normal annual tests, screening should be continued every 2 y. If high risk, continue annually |
| Northwest Territories | No | – | – | 18+ | After three normal annual tests, screening should be continued every 2 y |
| Yukon | No | – | – | 18+ | After three normal annual tests, screening should be continued every 2 y |
| Nunavut | No | – | – | 18+ | After three normal annual tests, screening should be continued every 2 y If high risk, continue annually |

^a Has a provincial computerized information system for cytology, which may have been implemented before inception of full programme. From Health Canada (2002)

for enforcing the regulations, and CDC provides technical and scientific support to CMS. The CMS central office in Baltimore, Maryland, establishes CLIA programme policies and oversees and coordinates the work of 10 CMS regional offices. The regional offices are responsible for enforcing the CLIA regu-

lations among the cytology laboratories in their jurisdictions. These regulations were amended in 1991 and have been further streamlined over the last decade. Some issues still exist regarding interpretation and review of screenings and review for false negative tests, but some improvements in cervical cancer

screening technology such as thin-layer cytology, liquid-based preparations and HPV DNA testing may increase the sensitivity and specificity of testing.

To ensure the reliability of cytological tests, the following steps must be performed and monitored correctly and adequately (Lawson *et al.*, 1997):

Table 52. Self-reported screening within the previous three years by age group and province, Canada, 1998–99

| Age group | Canada % | BC % | ALTA % | SASK % | MAN % | ON % | QUE % | NB % | NS % | PEI % | NFLD % |
|---------------|----------|------|--------|--------|-------|------|-------|------|------|-------|--------|
| 20–29 | 80 | 76 | 80 | 91 | 86 | 77 | 81 | 84 | 92 | 84 | 92 |
| 20–39 | 86 | 83 | 85 | 85 | 88 | 87 | 82 | 96 | 92 | 89 | 91 |
| 40–49 | 82 | 79 | 89 | 82 | 83 | 80 | 83 | 80 | 90 | 83 | 85 |
| 50–59 | 77 | 79 | 70 | 74 | 90 | 77 | 78 | 73 | 69 | 77 | 67 |
| 60–69 | 60 | 58 | 72 | 64 | 73 | 60 | 56 | 54 | 59 | 68 | 53 |
| Total (20–69) | 79 | 77 | 81 | 80 | 85 | 78 | 78 | 80 | 83 | 82 | 80 |

Source: National Population Health Survey, 1998/99
From Health Canada, 2002

ALTA, Alberta; BC, British Columbia; MAN, Manitoba; NB, New Brunswick; NFLD, Newfoundland; NS, Nova Scotia; ON, Ontario; PEI, Prince Edward Island; QUE, Quebec, SASK, Saskatchewan

- Patients must be properly examined and cervical cells from the transformation zone must be sampled.
- Specimens must be properly collected and labelled.
- Laboratory requisition forms must be complete and contain sufficient information.
- Cytological tests must be evaluated in a CLIA-certified laboratory.
- Laboratory reports must be reviewed to identify patients who require follow-up.
- Health-care providers and their patients must be notified of the screening results and any follow-up indicated.
- Appropriate follow-up must be taken.
- Any substantive discrepancy between clinical, cytological and histological findings must be resolved by the referring clinician and an anatomic pathologist.

In 1988, the first Bethesda System Conference was organized to streamline and update the use of cervical cancer screening terminology. This conference established the Bethesda System, to simplify and improve communication of findings between

cytopathologists, clinicians and patients (see Chapter 2). The Bethesda system, with refinements made in 1991 and 2001, is widely accepted in the USA and Canada (Solomon *et al.*, 2002).

Canada

Cervical cancer screening programmes have adopted a system closely resembling the 2001 Bethesda System to classify cytological specimens on the basis of their perceived adequacy for interpretation: satisfactory for interpretation or unsatisfactory. The "unsatisfactory" category is used when the smear quality is inadequate for interpretation (Health Canada, 2002).

Three provinces reported on specimen adequacy for smears taken in 1998, before the changes resulting from the 2001 Bethesda System conference. The percentage of unsatisfactory smears varied from 0.3% to 3.8% (Health Canada, 2002).

Performance indicators

United States

While estimates of screening participation in the USA are readily available, they come primarily from self-reported data collected in the BRFSS and NHIS national surveillance programmes.

These figures are not validated and may represent either over- or under-estimates. Few if any measures of adequacy of interpretation other than those required by CLIA exist to monitor accuracy. Little information is available at the national level on such performance indicators as proportion of unsatisfactory tests, proportion of women not receiving indicated follow-up and the proportion of women diagnosed with cancer who were never or rarely screened. Information that is not population-based has come primarily from case series and from the quality control experience of cytology reference laboratories (Sung, 2001; Krieger & Naryshkin, 1994; Tabbara & Sidawy, 1996).

In the NBCCEDP, performance indicators measure adequacy and timeliness of screening and follow-up, the proportion of unsatisfactory tests and the proportion of women never or rarely screened who enter the programme each year. A target has been set of 20% of women screened annually who have rarely or never been screened. In addition, to monitor over-utilization of screening, a target of 75% has been established as the proportion of women who are moved to a triennial test interval if they have had three suc-

cessive confirmed negative programme tests over a five-year period.

Canada

Objective information on cervical cancer screening in Canada is not readily available in most provinces on a routine basis. Furthermore, administrative databases at the provincial level, such as physician billing data, cannot be used for the most part as they may not include separate billing codes for Pap tests and, even if they do, will not allow distinction between tests done specifically for screening in asymptomatic women and those done for follow-up. Self-reports from women in national and provincial health surveys and small-area studies are thus the only sources of information.

The only cervical cytology performance indicators currently available relate directly to cytology laboratories. The indicators collected are:

- Cyto-histological correlation rates for each grade of squamous intraepithelial lesion and for carcinomas measured against follow-up surgical material or clinical outcome.
- False-negative rates. The false-negative rate of the laboratory and of individual cytotechnologists should be separately measured. A false-negative result is defined as a screening miss, in a satisfactory smear, of an abnormality graded as ASCUS or worse, or an equivalent if an alternative terminology is in use (Canadian Society of Cytology, 1996).
- The rate of satisfactory and unsatisfactory specimens at the laboratory and slide-taker levels.
- The total number and rates of abnormal gynaecological diagnoses and specific diagnostic categories for the laboratory.
- Turnaround time. Clinicians and laboratories should establish a mutually agreed turnaround time

from the date the specimen is received in the laboratory to the date of the final report; an optimal time could be approximately one month.

Latin America and the Caribbean

This region includes 28 countries, ranging from the small island states in the Caribbean to Brazil.

Organization

Health services in Latin America and the Caribbean began offering screening services with cervical cytology in the early 1960s, through family-planning services and later within primary health care. Table 53 provides information about the current status of cervical cancer screening programmes in the region. There is considerable variation with regard to the age range of the target population, but most of the guidelines recommend screening every three years. To what extent these guidelines are followed by health-care providers is unknown.

Several countries have attempted to set up organized screening programmes, often achieving partial organization. Chile and Colombia have had a national organized programme for at least 15 years, with documented improvements in quality and coverage, as well as decreased mortality in Santiago, Chile and decreased incidence in Cali, Colombia.

In Chile, the programme was reorganized in 1987, focusing on improving follow-up of women screened positive and involving all public laboratories that served the programme in a quality assurance system. No data are available on rates of follow-up, but the country has a large health infrastructure, a public subsidy for health insurance for 70% of the population, with 30% paying for private insurance. In both these systems, services for treatment of pre-malignant lesions are

widely offered and access to cancer treatment is guaranteed. In 1990, 40% of women aged 25–64 years had been screened in the past three years, according to a national survey, and participation increased to 66% in 1997, remaining at a similar level in 2000 (68%). The programme is centrally supervised by the Ministry of Health, but managed by each health region. A management agreement for budget allocation is signed between regions and the Ministry of Health, in which specific services and outcomes are agreed upon.

In Colombia, organization of a national programme started in 1989 and guidelines were approved in 1990. These guidelines placed emphasis on diagnosis and treatment for women with a positive screening result. Health sector reform in the 1990s privatized and decentralized the delivery of health care, but special legislation ensured preventive care including cervical cancer screening.

Extent of use

In the absence of country-wide population registries, participation in cytological screening has been assessed through surveys. One source of information is a series of Health and Fertility Surveys sponsored by the US Agency for International Development (USAID) in countries in which they have a reproductive health programme. A probabilistic sample of women aged 15–49 years are interviewed in their homes to investigate various aspects of reproductive health. Several countries collect data on screening for cervical lesions by asking women if they had a Pap test in the last 12 months. Table 54 shows participation in cytological screening in countries for which data are available. The lowest participations are observed in Jamaica (15.3%) and Nicaragua (20.5%). Ecuador and Costa Rica report high participation (72.2% and

Table 53. Cervical cancer screening programmes in Latin American countries, 2004

| Country | State of cervical cancer screening programme | Screening policy | Lifetime no. of smears |
|---|--|--|------------------------|
| Mexico | In 1996, a national guideline was approved by consensus with the participation of all major health-care providers. Various studies have shown deficiencies in quality services, including cytology. | Age 25+ of all Every 3 y | 13+ |
| Guatemala El Salvador Honduras Nicaragua Dominican Republic | No organized cervical cancer screening programme exists in these countries. Although cytology is performed through family-planning programmes, no follow-up of women screened positive is ensured. Initial attempts to pilot and evaluate visual inspection have been carried out in Nicaragua and El Salvador. Health-care systems in these countries are fragmented and coverage for women is restricted to maternal health. | 30–45, annual 30–59, every 2 y 25–59, every y | 15 15 34 |
| Costa Rica | Several attempts have been made to organize a cervical cancer screening programme. They have been able to centralize the cytology laboratory and maintain good quality standards. Nearly 90% of the population is covered by insurance and high coverage of cervical cytology has been reported, but no significant reduction in incidence or mortality from cervical cancer. | 20–59, every 2 y | 17 |
| Panama | Screening has been available, but no organized screening programme is in place | 15+, every 3 y | 17+ |
| Cuba | A programme is in place; coverage has been estimated at 70% using records reported from provincial health departments. No reduction in mortality has been observed. | 25–59, every 3 y | 11 |
| Colombia | Has had a cervical cancer screening programme since 1989. With health-sector reform in which multiple health-care providers emerged, major efforts were made to maintain the programme and improve coverage. Decreased incidence has been observed in data from the Cali cancer registry. | 25–64, every 3 y | 13 |
| Venezuela | Efforts were made at the state level to improve follow-up of women screened positive by promoting out-patient care and use of colposcopy and LEEP. | 25–64, every 3 y | 13 |
| Ecuador | In the city of Quito, a cytology quality assurance programme was implemented through a large NGO in charge of cancer care (SOLCA); more recently coverage has been extended and efforts directed to screen women aged 35–59 years every five years. | 30–59, every 5 y | 7 |
| Peru | National guidelines were issued in 2000. Cervical cytology is available. A large project in the province of San Martín has improved capacity and is leading the way for other provinces to improve their programmes. | 25–59, every 2 y | 17 |
| Bolivia | The Ministry of Health has recognized the importance of the problem, but cervical cancer screening, diagnosis and treatment were recently excluded from the maternal insurance package. | | |
| Paraguay | A recent needs assessment was conducted, but no cervical cancer screening programme has been organized | | |
| Uruguay | Presents among the lowest cervical cancer mortality rates in Latin America; opportunistic screening is offered in health care services | | |
| Brazil | A large cervical cancer screening programme was initiated in 1996 through the National Cancer Institute. In 1998 a large campaign to reach women who had never been screened was launched. Efforts are now being made to incorporate the screening programme into the primary care family health programme. | 25–60 every 3 y | 11 |
| Argentina | Cervical cytology is widely offered throughout the country. Cervical cytology programmes have been organized at the provincial level. No quality assurance programme is in place. | 35–64, every 3 y | 10 |
| Chile | A cervical cancer programme was reoriented in 1987, with clear attention to improving quality of cytology and follow-up of women screened positive before increasing coverage. Mortality from cervical cancer has begun to decrease, particularly in Santiago where the programme started. | 25–64, every 3 y | 13 |
| Haiti | No programme | | |
| Dutch/ English- speaking Caribbean | No organized programme exists in any of the 14 countries, although over the past 15 years several attempts have been made. In 2003, the Ministers responsible for health of the Caribbean Community (CARICOM) placed cervical cancer high on their agenda and 10 countries have assigned new resources to this area. | | |

Table 54. Proportion of women reporting having had a test in selected countries of Latin America and the Caribbean

| Country (year) | Age | Percentage | N | Source |
|--------------------------------------|-------|------------|--------|------------------------------------|
| <i>Within the last twelve months</i> | | | | |
| Costa Rica (1993) | 15–49 | 66.9 | 3618 | H&F Surveys ^a |
| Ecuador (1994) | 15–49 | 72.2 | 13 582 | H&F Surveys ^a |
| Honduras (1996) | 15–49 | 55.4 | 7505 | H&F Surveys ^a |
| Jamaica (1997) | 15–49 | 15.3 | 6384 | H&F Surveys ^a |
| Nicaragua (1998) | 15–49 | 20.5 | 7150 | H&F Surveys ^a |
| Paraguay (1996) | 15–49 | 49.1 | 6465 | H&F Surveys ^a |
| Peru (1996) | 15–49 | 42.9 | | H&F Surveys ^a |
| Dominican Republic (1996) | 15–49 | 44.8 | | H&F Surveys ^a |
| <i>Ever screened</i> | | | | |
| Brazil | | | | |
| São Paulo (1987) | 15–69 | 68.9 | | Nascimento <i>et al.</i> (1996) |
| Pelotas (1992) | 20–69 | 65.0 | | Dias-Da-Costa <i>et al.</i> (1998) |
| Pelotas (2000) | 20–69 | 72.0 | | Dias-Da-Costa <i>et al.</i> (2003) |
| Mexico | | | | |
| Morelos (1996/97) | 15–49 | 63.3 | | Lazcano-Ponce <i>et al.</i> (1996) |
| Guadalajara (1997) | 15–49 | 81.6 | | Jiménez-Pérez & Thomas (1999) |
| Mexico City (1997/98) | 14–54 | 45.0 | | Aguilar-Pérez <i>et al.</i> (2003) |
| Costa Rica | | | | |
| Guanacaste (1995/96) | 18+ | 87.8 | | Herrero <i>et al.</i> (1997) |
| <i>In the past three years</i> | | | | |
| Chile (2000) | 25–64 | 68.3 | | CASEN Survey ^b |
| Peru | | | | |
| San Martin (2000/03) | 25–59 | 40.3 | | Ferreccio <i>et al.</i> (2004) |

^a Unpublished data from USAID/CDC Health and Fertility Surveys, for countries that receive assistance for a reproductive health programme.

^b Unpublished data from Employment Household Interview Survey

Source: www.cdc.gov/reproductivehealth/logistics/global_rhs.htm [accessed 25 April 2004]

66.9%, respectively), largely due to family-planning programmes in their primary health-care infrastructure.

In other Latin American countries not covered by Health and Fertility Surveys, various studies have assessed screening participation in the population. The proportions of women ever screened by cytology were reported as 68.9% among women aged 15–69 years in São Paulo, Brazil (Nascimento *et al.*, 1996); 65% among women aged 20–69 years in Pelotas, Brazil (Dias-Da-Costa *et al.*, 1998); 63.3% among women aged 15–49 years in Morelos, Mexico

(Lazcano-Ponce *et al.*, 1996); 81.6% in Guadalajara, Mexico (Jiménez-Pérez & Thomas, 1999) and 45% in Mexico City (Aguilar-Pérez *et al.*, 2003). Consistent with the 1993 fertility survey, in a sample of women aged 18 years and older in Guanacaste province, Costa Rica, 87.8% reported having had a cytological test in their lifetime (Herrero *et al.*, 1997); and in 2000–03, 44.3% of women aged 25–59 years in the province of San Martin, Peru, declared having had a test in the last three years (Ferreccio *et al.*, 2004), consistent with the figure reported in the 1996 survey. The pro-

gramme in Chile, using a periodic household survey to ask women aged 25–64 whether they had a test in the last three years, reported participation of 68% in the year 2000. Other countries collect similar data from periodic surveys, but these are seldom published. The quality of such information is difficult to assess. In Latin America, higher participations have been found in women who are aware of the benefits of screening (Lazcano-Ponce *et al.*, 1999b; Aguilar-Pérez *et al.*, 2003), have high socioeconomic status, as measured by schooling or housing conditions (Torres-Mejia *et al.*, 2002;

Dias-da-Costa *et al.*, 2003) and who report satisfaction with previous care (Alvarez, 1996; Brenna *et al.*, 2001).

Quality of cytology

Several cytology laboratories in Latin America and the Caribbean perform quality assurance procedures, by studying reproducibility, performance evaluation or cyto-histological correlation. In Mexico, two studies on reproducibility of cytological testing, as measured by weighted kappa, concluded that intra-class agreement was low for dysplasia and carcinoma *in situ* but higher for invasive carcinoma (Alonso de Ruiz *et al.*, 1996; Lazcano-Ponce *et al.*, 1997a). Kappa coefficients ranged from -0.02 to 0.17 for moderate and severe dysplasia between the two studies and were 0.29 and 0.36 for invasive carcinoma. One study (Lazcano-Ponce *et al.*, 1997a) also assessed reproducibility for histology of cervical lesions among 30 pathologists; kappa coefficients were 0.07 for severe dysplasia, 0.23 for moderate dysplasia and to 0.64 for invasive carcinoma. Following these studies, a major initiative was undertaken to improve cytology in the country.

An initial evaluation of all cytology laboratories of the Mexican Ministry of Health found that only 70% of microscopes were in satisfactory condition; deficiencies in the supply of reagents and in laboratory facilities were reported. An evaluation of the performance of cytotechnicians was conducted by reviewing sets of slides previously diagnosed by an expert panel. In this exercise only 16% of cytotechnicians achieved a good or excellent score, which meant at least 70% of simple agreement (Flisser *et al.*, 2002). A quality assurance programme was initiated which included improving physical infrastructure, training of cytotechnicians and establishing a performance evaluation programme. In pre-course tests, 21% of the cytotech-

nicians achieved a good or excellent score; the percentage increased to 69% after the course. At a third assessment six months to one year later, the proportion with good or excellent scores decreased to 56%, still much better than the situation found at baseline.

Seven countries in Latin America participate in a joint quality assurance programme (RedPAC). The programme includes on-site evaluation and technical support, as well as periodic performance evaluation, measured as agreement between the cytotechnicians and an expert panel. Improvements were observed in Costa Rica, Ecuador and Mexico, where in three consecutive years (1999–2001) weighted kappas rose from 0.43 to 0.65, from 0.44 to 0.63 and 0.52 to 0.63 respectively (Luciani *et al.*, 2003). The improvement was attributed mostly to the reduction in the proportion of slides that were undercalled. Other areas of concern have also been addressed, such as the proportion of inadequate slides, which was reduced after training programmes from 3.71% to 1.98% in Ecuador and from 4.47% to 2.0% in Mexico. In three other participating countries (Bolivia, Peru and Venezuela), no significant change has been observed and agreements (weighted kappas) were under 0.40. The only data from Brazil are for the city of São Paulo, where an analysis of cytology and the corresponding histology in a sample of 157 cases from a major laboratory found agreement in 75.8% of the cases; cytology underestimated 17.2% of the lesions (Di Loreto *et al.*, 1997).

Performance indicators

Major efforts and investments to increase participation have been made in many Latin American countries, but other aspects of the programme have not received equal attention. In Mexico, the cytology-based cervical cancer

screening programme has been able to avert only 13% of potentially preventable deaths, as estimated by Lazcano-Ponce *et al.* (1996). This situation has been attributed to low accuracy of the test or quality of cytology in these settings (Alonso de Ruiz *et al.*, 1996). A basic element of a screening programme is to provide diagnostic and treatment services for those screened positive, but this has been neglected in many countries. In a study in Peru, only 25% of women who were screened positive received appropriate follow-up (Gage *et al.*, 2003); a similar situation was found in El Salvador (Robles, 2004). In a municipality of São Paulo, Brazil, 78.3% of women with a positive cytological result received adequate treatment in primary care services; but when they were referred to secondary care, only 37.4% had adequate follow-up (Santiago & Andrade, 2003).

Overall, cytological testing has been offered throughout Latin America and the Caribbean, but most countries have failed to organize screening programmes. Research is under way to assess the potential effectiveness of low-cost technology such as visual inspection methods and of HPV DNA testing in various populations of Latin America and the Caribbean.

Africa

Screening is difficult to achieve in Africa partly because of significant competing, urgent health-care needs, in particular the HIV epidemic, and partly because of poorly functioning health-care delivery systems.

A review on the functioning of health-care systems undertaken by the World Health Organization (2000) rated and ranked these systems worldwide, revealing that among the 191 WHO Member States, most of the least functional health-care delivery systems are in Africa.

To make an impact on the epidemiology of cervical cancer, as with any

screening programme, national organized programmes that achieve high participation are required. Research in African settings confirms that integration of screening services into the existing health-care systems is the only way that high participation rates could be achieved (JHPIEGO, 1997). Other research is attempting to find technological solutions (screening methods that are cheaper, that do not require laboratory back-up, or that allow immediate treatment, with low-technology and low-cost treatment options) to address some of the health system inadequacies that are prevalent in Africa and some research is looking at other treatment options (Adewole *et al.*, 1998; Darwish & Gadallah, 1998). In addition, such efforts may provide pilot sites from which national programmes can evolve.

Organization

Only South Africa has an official national cervical screening policy, which recommends three cytological tests for women over the age of 30 years at ten-year intervals. However, the need for national policy has been articulated in many countries in Africa (Adanu, 2002). Absence of policy has resulted in lack of action and in screening of women at inappropriate ages (Ngwalle *et al.*, 2001; Konje *et al.*, 1991); in addition, facilities for treatment of precancerous lesions are often inadequate (for example, Tanzania: Ngwalle *et al.*, 2001).

There are indications, however, that even in the absence of formal policy, many countries have plans to implement programmes. In Malawi, a programme for cervical cancer screening and early treatment, as a partnership between the Ministry of Health and Population and an international non-governmental organization, has been initiated and a nationwide campaign is planned which will start in the

southern part of country (Anonymous, 2002). In Zimbabwe, screening based on visual inspection with acetic acid (VIA) has been under consideration (Chirenje *et al.*, 2000), but it is not clear if this is a national programme and whether this is a priority for Zimbabwe (Rutgers & Verkuyl, 2000). The current state of the Zimbabwe health service suggests that rapid implementation is highly unlikely. Cameroon has had an operational cervical screening programme since 1992, but services are provided only in two major cities and the cost is such that most women do not have access to the service (Robyr *et al.*, 2002).

It is clear that access to screening is poor for most women in Africa (Kenya and Sierra Leone; Burkina Faso, Senegal, Ghana, Nigeria: Brown & Morgan, 1998) and this results in late presentation of women at treatment centres (Gharoro *et al.*, 1999; Were & Buziba, 2001).

Although policy frameworks are useful and their absence can lead to irrational programmes and confusion (Moyo *et al.*, 1997), they are not sufficient to ensure implementation; processes to ensure that policy is understood are essential (Anonymous, 2001). In South Africa, there is now a national initiative to implement a national cervical screening policy, which is probably the best developed in the region and might provide an example for other countries to follow. South Africa is, however, different from many other countries in the region in having a relatively well developed laboratory-based capacity to provide cytology services.

South Africa

The South African National Cancer Control Programme was adopted as official government policy in 1997. Policy development is a national function, but implementation and delivery is a provincial (and more recently a local

government) function. While policy indicates what is required, it often does not explain how services should be developed. This leads to unrealistic expectations at the policy level and frustration for implementers. After various attempts to implement screening by promoting the policy, a national strategy spearheaded by the national Department of Health was initiated. The main objectives of this strategy are to strengthen the existing health-management systems to implement, monitor and sustain the cervical cancer screening programme; to ensure maximum coverage of the target population; to ensure provision of facilities for screening and treatment of precancerous lesions and develop referral links between screening and treatment services; to increase awareness of cervical cancer and its prevention; and to ensure monitoring and evaluation of the programme.

Despite this policy framework, progress in cervical cancer screening has been slow and hard to achieve. The nine provinces in South Africa are at different levels of development and there are resulting differences in implementation. Two provinces (Limpopo and Eastern Cape) are predominantly rural in nature and poor, with health-care delivery systems that function poorly. Others (Gauteng and Western Cape) are urban and have good resources. The other provinces are located between these two extremes.

Study of the South African situation shows that where policy does exist, it is more likely that resources will be dedicated to cervical screening services. Thus in the Western Cape province, cervical screening has been identified as a priority service and development of services has been included in the key performance indicators or in performance agreements of health-system managers. Similarly in KwaZuluNatal, cervical screening is a performance target for districts.

These two provinces have the greatest access to screening services. In three provinces budgetary allocation for cervical screening exists. While in provinces such as Limpopo and Mpumalanga, poor transport systems are considered a barrier to implementation, as this hampers the delivery of slides to laboratories. However, other possibly poorer provinces have found creative ways of overcoming this problem, for example by linking cervical screening with the tuberculosis programme and using the same laboratory transport system. This illustrates the value of integrating cervical screening into existing health-care services. In another case, private taxis transport the slides as part of their routine runs. While in all provinces there are colposcopes at the district level, there may be no trained staff available to use them. In one rural province a partnership with a non-governmental organization has been set up to improve access to screening services and three of the five districts comprising the province report offering services. Nonetheless, in some instances women in the wrong age group are being screened. However, it is becoming increasingly clear what kinds of intervention are required in order to assist provinces to implement a programme. Pilot programmes have been set up and manuals for managers have been developed.

The South African experience has shown the need to provide health service managers with tools to assist them with practical aspects of implementation. For example, one tool indicates how to work out the target population and thus the number of smears to be taken in a year and the workload and equipment needs at each service site. Another tool indicates what clinic-based data to collect and how to estimate the participation rate and the follow-up in each service delivery area.

The rest of the region

No data on cervical cancer screening are available from northern Africa.

In a review of cervical cancer diagnosis and treatment in countries of east, central and southern Africa, a lack of policy guidelines, infrequent supply of basic materials and absence of suitably qualified staff were the common reasons reported for the low percentage of women actually screened. The review found that 95% of the facilities at primary care level had the basic infrastructure to offer cervical screening (Chirenje *et al.*, 2001). However, once slides were taken, there was no way to send them for reading and limited access to referral pathways to treat patients. In Botswana, for example, cervical screening is limited because few facilities have easy access to laboratories to read cervical smears (Baakile *et al.*, 1996).

Given the competing demands on health-care services, the only way in which cervical screening programmes will gain the required political support is if they are developed in such a way as to benefit the overall functioning of the health-care system. The imperative of high coverage requires that services be decentralized, thus integrating cervical screening into the existing health-care services offers the best approach to reducing cervical cancer mortality. However, such integration is not simple, as much of the organization of health services in Africa is donor-driven, often resulting in single-service facilities such as family-planning services. In a study in Kenya, integration of cervical screening into family planning clinics was reported to be feasible and acceptable to both providers and patients, and would benefit the patients screened. However, only a small percentage of women utilize these services and in the Kenyan study, 43.5% of women were less than 30 years of age, so that the potential reduction in cervical cancer mortality is limited (Claeys *et al.*, 2003).

It has been suggested that many African countries are not able to implement screening and that cervical cancer is not a priority (McCoy & Barron, 1996; Rutgers & Verkuyl, 2000) or that it is important but impossible to achieve (Wilkinson, 1997). However, the benefits that accrue from setting up a cervical screening service can be extended to other services, so that referral pathways, laboratory services, equipment supply systems and monitoring systems, once operational for cervical screening, can be extended to other health-care needs or be developed in tandem with and complement existing systems (Fonn, 1997).

There are neither the resources nor the human capacity in Africa to develop vertical programmes (single-service programmes with staff working only in that programme, frequently with unique conditions of service and unlinked independent supply and monitoring systems, unrelated to other health-care services often provided in adjacent sites). Yet existing resources can be marshalled and applied to cervical screening. An approach that recognizes and builds health-systems capacity to deliver cervical cancer screening can improve the overall functioning of health services in general.

Asia

Data on cervical cancer screening from western and south-central Asian countries were available to the Working Group only from Israel and India. Data are also available for a number of south-eastern and far eastern Asian countries.

Israel

As the incidence rate of cervical cancer in Israel is very low, the official policy is not to screen average-risk women. However, the National Insurance Plan reimburses cytological testing for women aged 35–54 years once every three years. In practice, many women are screened, usually at

shorter intervals than recommended, with generally low-quality cytology. In addition, most women attending screening are of high socioeconomic status and probably are not the women at highest risk. About 150 000 tests are performed every year.

India

India has a National Cancer Control Programme that supports the principle of early diagnosis and treatment of cancer of the cervix. Although cytological testing is available to a limited population of mainly urban women, there are no screening programmes (Dinshaw & Shastri, 2001; Shanta, 2001; Varghese *et al.*, 1999). India is a high-risk country for cervical cancer (Shanta *et al.*, 2000; Sen *et al.*, 2002). Women at highest risk of cervical cancer are those over the age of 35 years, in low socioeconomic strata and with little or no education. Given that over 80% of the population lives in rural areas, screening programmes need to work within this sector (Dinshaw & Shastri, 2001; Sankaranarayanan *et al.*, 2001; Shanta, 2004). Cytology-based screening is not regarded as practical or achievable in India (Dinshaw & Shastri, 2001).

Visual inspection-based approaches to cervical cancer screening such as VIA have been extensively investigated in India, although their long-term efficacy in reducing the burden of cervical cancer has not yet been demonstrated (Sankaranarayanan *et al.*, 2001; Basu *et al.*, 2003). Visual inspection is now regarded as the best option for proposed cancer control programmes, with training curricula and courses developed by international organizations such as IARC and JHPIEGO (Shanta, 2001). The Bill and Melinda Gates Foundation funds the Alliance for Cervical Cancer Prevention which supports projects in India, including through IARC (<http://www.alliance-cxca.org/index.html>).

The advantages of visual inspection methods are the lower costs than cytology and the short training period required for health workers, including the ability to train nursing and non-medical workers (Basu *et al.*, 2003; Sankaranarayanan *et al.*, 2003). Some 457 000 women (0.25% of all eligible women at risk) have participated in screening studies of visual inspection methods (Shanta, 2004). The results indicate that the women accepted screening by visual inspection with acetic acid or magnification after application of acetic acid (and colposcopy and cryotherapy) by nurses, that a moderate level of compliance with screening and treatment was reached, and that these methods have higher sensitivity and lower specificity than cytology in the Indian setting (Basu *et al.*, 2003). The low specificity, however, that causes high rates of referral and treatment, was a major limitation. Nevertheless, visual inspection has been recommended as the immediate option for cervical cancer control initiatives in 54 districts of India (Shanta, 2001; Sankaranarayanan *et al.*, 2001).

Viet Nam

Viet Nam does not have a national screening programme. Research activity relates mainly to HPV prevalence. A substantial difference in the prevalence of cervical cancer and of HPV infection between the north and south of the country are regarded as due to the greater isolation of north during the decades of war and socialist economy (Pham *et al.*, 2003). A survey carried out in 1997, within the framework of an IARC multicentre study, found that HPV infection was rare in Hanoi and five-fold higher in Ho Chi Min City (Pham *et al.*, 2003).

In November 1998, the Western Pacific Regional Office of WHO collaborated in strengthening cervical screening programmes with a series of

training sessions on cytological screening, and pilot projects were established in Hanoi and Ho Chi Minh City. In co-operation with the Viet/American Cervical Cancer Prevention Project, the feasibility of cytological screening in Viet Nam was established by a formal cost-effectiveness analysis, and population-based cytological screening services were established in 1999 in Ho Chi Minh City (Suba *et al.*, 2001; Le Van *et al.*, 2004). Pilot-scale screening is continuing to assess whether cervical cancer constitutes a public health problem of sufficient magnitude in northern Viet Nam to warrant the initiation of population-based screening.

Thailand

Thailand has attempted to establish a cervical cancer prevention programme for 30 years, with activity in selected districts through maternal and child health or family-planning services (Gaffikin *et al.*, 2003). In 1997, a national policy for cervical cancer proposed that screening be offered to women aged 35–54 years with a Pap test every five years and, in the north-east of Thailand, using visual inspection methods. However, surveys have found that few women know about the Pap test and few have ever been screened (Kritpetcharat *et al.*, 2003; Tinker, 2004). National annual participation is estimated to be no more than 5% (Gaffikin *et al.*, 2003). A mobile unit programme offering cytological testing was established in 1993 (Swaddiwudhipong *et al.*, 1999) and a demonstration programme of visual inspection methods in 2000 (Gaffikin *et al.*, 2003). The latter programme concluded that a single-visit approach with VIA and cryotherapy by nurses was safe, acceptable and feasible and could be considered in areas where setting up cytological screening is unlikely (Gaffikin *et al.*, 2003). Concerns have been raised, however, about potential

overtreatment due to the low specificity of VIA (Walraven, 2003). Other impediments to the use of VIA in a population-based programme include the need for standardized initial training and continuing education, and that no study has shown that VIA screening reduces cervical cancer incidence or mortality (Walraven, 2003).

Philippines

Cervical cancer is the second most common cancer in women in the Philippines. The Department of Health in the Philippines has proposed an organized cervical cancer screening programme, with recommendations for regular cytological tests every three years, although a recent policy shift has recommended visual inspection methods (Ngelangel & Wang, 2002; Ngelangel *et al.*, 2003). Changes in public health policy, including aspects related to education of screening personnel, strategies for ensuring compliance with screening and health insurance coverage for preventive services, have been mentioned as barriers to the development and implementation of a screening programme (Ngelangel *et al.*, 2003). The lack of a skilled workforce is also an issue. The Philippines Cancer Society is involved in cytological testing, although this is not widely available (<http://www.kanser.com.ph>).

Republic of Korea

In Korea, a national screening programme for cervical cancer started in 1999. Cytological screening is recommended every two years for women 30 years or older, of whom 33% had a test in 1999–2000. The provision of services is insurance-based, administered by the Ministry of Health and Welfare. This insurance covers the costs to individual women of screening for cervical cancer selectively for lower-income women. Discussion and planning are continuing in order to define the

screening interval, upper age limit, the test and quality control procedures.

China

Occurrence of cervical cancer is largely unrecorded in China, but is known to be higher in rural areas; mortality from cervical cancer is around the level in the USA (Belinson *et al.*, 1999). Mortality has decreased over the past 25 years, maybe as a result of the major social changes and the health programme set up by the Chinese government after the founding of the People's Republic in 1949, in particular, the outlawing of prostitution and closure of brothels, and establishment of health facilities in factories and other work units, and specific public health programmes to screen for and treat sexually transmitted diseases (Li *et al.*, 2000). Cervical cancer accounted for only 1% of cancers in women in 1995 (Wang, 2001). Cancer prevention is not a high priority and lacks government funding. There is no national screening programme and cytology-based services are patient- or employer-initiated. Women who have insurance can attend a hospital for screening. While government agencies cover employees for insurance, private employees may or may not be covered. Screening is now less common than 10 years ago and is becoming more of a personal activity, organized at the level of individual companies or groups and subject to market forces. This change has led to fewer individuals being screened (Wang, 2001).

Small centres offer a screening service, mainly associated with universities or small studies. In the past, the work unit was the sole channel through which screening could be offered and was responsible for organizing any screening that took place. Health professionals hope that the new medical insurance system will cover cancer screening and prevention (Wang, 2001).

In Shandong Province, a cytological screening programme started in 1970–72 and covered 1.5% of the female population, before government funding was withdrawn; screening then continued in only a few areas (Li *et al.*, 2000).

More recently, a pilot study in a high-risk province (Shanxi province) conducted a trial of cytological testing and HPV direct and self-testing in 1997 among women aged 35–45 years (Belinson *et al.*, 2003).

Three national demonstration centres will be set up for screening, organized through field stations in women's and children's health centres or village clinics.

Hong Kong

Cytological screening has been offered for 10 years in Hong Kong by the Department of Health through 34 gynaecological clinics and health centres, including maternal and child health centres, social hygiene clinics and others such as family planning, for which the service statistics indicate around 100 000 tests per year in 1997–2001 (<http://www.famplan.org.hk/fpahk/en/template1.asp?style=template1.asp&content=info/statistics.asp&type=3>). It has been estimated that the Department of Health and Family Planning was responsible for 24% of Pap tests, the Hospital Authority for 15% and private hospitals and medical practitioners for 37% in 2003 (Asian HPV Summit, 2003). The existing cytological testing has not been part of an organized programme and has no target population, no screening register and no formal quality-control process.

Several surveys conducted in Hong Kong showed that around half of all women were not receiving cervical screening (Yeung & Cheung, 2003). The Shatin Community Clinic for the Prevention of Cervical Cancer was set up in 1995 to reduce the incidence of cervical cancer. It provides a free

service to women who have never been tested, without age restriction, and tested 20 000 women in 1995–99. In 1998, it received funding from the Hong Kong Cancer Society for an automated screening instrument, and has accreditation from the Australian laboratory accreditation authority. The clinic provides training in diagnostic cytology to the Chinese PLA General Hospital in Beijing.

A population-based cervical screening programme was to be launched by the Department of Health in collaboration with other health services providers in late 2003 or early 2004 (Yeung & Cheung, 2003), targeting women aged 25–64 years with three-yearly screening, recruitment being through invitation letters, publicity campaigns and community outreach. The programme will provide training for smear-takers, have a central register and establish quality assurance indicators.

Taiwan

In 1993, an estimated 40% of women in Taiwan had never been screened (Wang & Lin, 1996) and a programme of free mass screening was established as part of the national health insurance in 1995 (Chen *et al.*, 2002). An educational and cervical screening programme at 12 public health centres in Taipei was extended (Pair & Ruey, 1996), using outreach clinics in areas with inadequate medical facilities and offering training courses (Chen *et al.*, 2002). The goal of the programme is to achieve a screening rate of 40% in women 30 years or older, who are offered free three-yearly screening. The Central Department of Health monitors and evaluates the programme, which is delivered by the City and County Health Bureau and local health stations with follow-up of HSIL grades by local public health nurses. The programme has a central registry and a process for laboratory quality control.

Singapore

The 1998 National Health Survey reported that about two thirds of Singapore women had ever had a cytological test (Yian, 2000). Screening of sexually active women aged 20–69 years is carried out at 16 polyclinics, 1900 private medical clinics and hospitals and the Singapore Cancer Society, although no annual figures are available (Thamboo *et al.*, 2003). Women pay for the test but older age groups are offered a subsidy. In January 1999, the Ministry of Health launched a Cervical Cancer Education Program, with a recommendation for an annual test in the first two years and three-yearly tests thereafter (<http://www.hpb.gov.sg/hpb/haz/haz01123.asp>).

A coordinated national programme has been set up to start in 2004 (Asian HPV Summit, 2003, Dr Quek), with training programmes for smear-takers, a smear reporting system as in Australia, a system of audit and management guidelines for abnormal results. The full programme is expected to commence after a one-year pilot programme at selected primary health care clinics.

Japan

Organization and financing

Cytological screening for cervical cancer was introduced in selected regions of Japan in 1961. These early programmes were established and organized voluntarily by gynaecology practitioners in cooperation with local government officials. National government funding, initiated in 1967, led to implementation of screening programmes at a nationwide level. In 1983, the Health and Medical Service Law for the Aged was passed, which established cervical cancer screening as one aspect of cancer screening programmes to be implemented nationwide at each city, town or prefecture. Although national government funding for cancer screening was phased out in 1998 and the

Health and Medical Service Law for the Aged was virtually inactivated, leaving implementation to be decided by each regional government, the continuation of cancer screening programmes has been strongly advocated by the national government. Cervical cancer screening is now funded by each regional government. Women have to make an out-of-pocket payment of 10–30% of the total cost of the test, the proportion differing between regions.

In addition to the mass-screening offered by the regional governments, many women have the opportunity to participate in company-based cancer screening, often offered by employers as part of a health insurance and benefits package, or personal health examinations, usually including cervical cancer screening, at private clinics and institutions. Cervical cancer screening offered by these programmes is implemented under almost the same criteria as programmes sponsored by regional governments. In a questionnaire survey, from 216 completed questionnaires, 147 companies (68%) stated that they offered cervical cancer screening as part of their employee health check-up (Nagai *et al.*, 1998). Thus, a variety of screening programmes are available to most women.

Extent of use and method of screening

Since the passage in 1983 of the Health and Medical Service Law for the Aged, the screening protocol recommended by the national government has been offered to residents of all prefectures. The target population includes all women aged 30 years or above, with a screening interval of one year. Women are individually invited to participate. The test is performed by obstetricians/gynaecologists under speculum examination using a cotton swab, spatula, scraper or brush for

sampling. Interpretation of cytological specimens is carried out by certified cytotechnologists and cytopathologists; their certification is carried out under the auspices of the Japanese Society of Clinical Cytology. All cytotechnologists and cytopathologists are members of this society and in order to assure the quality of cytology screening, the society offers regular training and education courses in addition to renewal of certifications every four years, based upon stipulated conditions.

The results of screening are reported in a five-tier evaluation designated as Classes I to V, based upon a modified Papanicolaou classification. Although the tiered evaluation system was not incorporated in the Bethesda System of 2001, the use of only a written evaluation report is still not widely accepted among clinical practitioners in Japan and the five-tier cytology classification is still used to avoid misunderstanding and to facilitate reporting of the screening results. The five-tier evaluation consists of Class I as normal, Class II as inflammatory change, Class III as dysplasia, Class IV as carcinoma *in situ*, and Class V as invasive carcinoma, as deduced from cytological features. All Class III results and above are interpreted as screen-positive and a repeat cytological examination as well as a colposcopically guided cervical biopsy are recommended as secondary testing.

The accuracy of cervical cancer screening carried out in Miyagi prefecture as part of the nationwide programme showed sensitivity of 94.7%, specificity of 98.9% and a false negative rate of 5.3% by linkage analysis, when all women screened were compared with patients having invasive cervical cancer or carcinoma *in situ* who were registered in a regional cancer registry (Table 55; Yoshida *et al.*, 2001). False negative cases were defined as those diagnosed as having cancer, including carcinoma *in situ*,

within one year after the negative screening result.

Quality assurance control for cervical screening programmes is administered by Management Control Committees for Lifestyle-related Disease established in each prefecture. These committees monitor information regarding the total number of participants, participation rate, secondary screening rate and individual participation history for cervical cancer screening programmes in each city or town in all prefectures (Ministry of Health, Labor, and Welfare, 1998).

The only data on total participation numbers and rates, as well as screening results for the programmes provided by regional governments, are integrated at a nationwide level and published annually in a *Report on Elderly Health Care* by the Statistics and Information Department, Minister's Secretariat of the Ministry of Health, Labor, and Welfare. A participation rate of about 14–15% is reported. No similar comprehensive analysis is available for non-government-sponsored cervical cancer screening programmes, although the estimated overall participation, combining both government and non-government-sponsored programmes, has been estimated to be 24%. Few quality assurance controls exist for non-government-sponsored cervical cancer screening programmes.

Future perspectives

The low participation of the cervical cancer screening programmes has been a matter of concern. In 2000, the national government presented a 'National Health Promotion Movement in the 21st Century (Healthy Japan 21)', which included the goal of increasing the number of participants by more than 50%.

Another concern is to broaden the target population, taking into account an observed increase in the incidence

of carcinoma *in situ* and invasive cancer in younger women (Research Group for Population-based Cancer Registration in Japan, 2003). In April 2004, the Ministry of Health, Labor, and Welfare recommended that screening should be initiated at 20 years of age with an interval of two years.

Oceania

Australia

Cytological screening was readily available to Australian women from the 1960s but largely on an opportunistic basis. In 1988, however, the Australian Health Ministers' Advisory Council set up the Cervical Cancer Screening Evaluation Steering Committee, which recommended an organized programme that was established in 1991 and renamed the National Cervical Screening Program in 1995. The organized programme is a joint initiative of the commonwealth, state and territory governments to provide cervical screening by coordinating the local programmes in individual states and territories, each of which has adopted or endorsed the goals and priorities of the national programme and uses the same performance indicators and targets. States and territories are responsible for regional coordination and delivery of screening.

Cervical screening is available to all sexually active women between 18 and 69 years of age, with a two-year screening interval. Women are asked to give their consent to their details being entered in the local cervical cytology register, from which a reminder is sent two years after their last screen. If the test result is abnormal, the register sends a letter to the woman and her medical practitioner to help ensure that appropriate follow-up action is taken. Coordination and programme administration are funded jointly through a national and state government agreement that covers

Table 55. Accuracy of cervical cancer screening in Miyagi prefecture, Japan (Yoshida *et al.*, 2001)

| Screening result | Cervical cancer | | |
|-----------------------|------------------|---------|---------|
| | (+) ^a | (-) | Total |
| Positive ^b | 54 | 2099 | 2153 |
| Negative | 3 | 184 005 | 184 008 |
| Total | 57 | 186 104 | 186 161 |

^a Including carcinoma *in situ*
^b Class III+ and non-assessable cases

several health areas and outlines responsibilities for delivery of the national screening programme.

Extent of use and access

The screening programme offers a test every two years to all sexually active women from around age 18–20, or younger if appropriate, and up to age 69 at which time screening may cease after two normal test results within five years. Women 70 years and older who have never had a test, or who request one, are eligible for screening. Women who have an intact uterus and have no symptoms or history suggestive of cervical pathology are eligible. There are separate national guidelines for management outside of the screening programme for women with a history of high-grade cervical lesions or who are being followed up for a previous abnormal test result.

Education campaigns encourage eligible women and under-screened groups to attend. General medical practitioners take most Pap smears (80%); gynaecologists, women's health nurses, Indigenous health groups and sexual health and other clinics are other providers. The scarcity of medical practitioners, particularly women practitioners, in remote and rural parts of Australia limits access to screening test services, although women's health nurses may be avail-

able. Accredited cervical cytology laboratories read the slides and send the results to the state or territory screening register and also to the health-care provider who took the smear and to the woman.

The costs of a visit to a medical practitioner and the laboratory costs for reading the slide are reimbursed by Medicare, the national health insurance scheme funded by the Commonwealth government. The same is true for treatment. The woman's contribution varies, since some medical practitioners charge more than the Medicare reimbursement and the women themselves must fund the difference in the fee. For women who are eligible, there is no charge for visits to providers funded through Health Program Grants or by state governments.

In 1991, the year before the national programme began, 52% of women nationally had a screening test. In the programme in 2000–01, 61.8% of women had a test. Participation varied by state: 58% in Queensland, 60–63% in New South Wales, Western Australia, the Northern Territory, and the Australian Capital Territory, and 66–67% in South Australia and Tasmania (Australian Institute of Health and Welfare, 2003a). Nationally, 32% of women registered with the programme were re-screened within less than the recommended two-year interval in

1999–2000 and 2000–01 (Australian Institute of Health and Welfare, 2003b). Women known to be under-screened are those of low socioeconomic status or with indigenous or other culturally and linguistically diverse backgrounds, and women 60 years and older or from rural and remote areas (Department of Health and Aged Care, 2000). No identifier by indigenous status is available in screening registers. Published four-yearly mortality rates, however, show that death rates from cervical cancer are much higher in indigenous (11.4 per 100 000 in 1998–2001) than non-indigenous (2.5 per 100 000) women (Australian Institute of Health and Welfare, 2003b).

The computerized cytology registers set up in each Australian state and territory in 1989–99 record contact details of consenting women and the smear-takers forwarded by health-care practitioners; results of tests and identification of the reporting laboratory are sent directly by laboratories. All information is confidential. Around 1–3% of women choose not to be registered by name and de-identified demographic details and smear results only are recorded for them. All registers have a protocol to ensure that women with test abnormalities have appropriate follow-up.

Registry data are collated nationally at the Australian Institute of Health and Welfare, which has produced five annual reports on the performance indicators endorsed by the national screening programme, beginning with data for 1996–97 and continuing up to 2000–2001. Data standards in place ensure consistent and reliable data for performance indicators.

Government expenditure on screening with cervical cytology in 1994–95 was mainly (61%) through Medicare reimbursement for private medical services and some pathology, 23% was a direct national government contribution to the screening programme and 16% came from the local

resources of the states and territories (AusAID, 1999). In 1999–2000, Medicare expenditure on cytological tests and pathology was \$84.2 million, while national recruiting activities were allocated \$4.8 million over the three years. Funding to increase participation was introduced in November 2001 and offers incentives to medical practitioners for increasing participation by women who were not tested in the last four years.

Methods for assuring quality

The National Advisory Committee to the National Cervical Screening Program (Advisory Committee on Cancer Prevention, 2000) has five working groups with members from all programmes, health professionals (pathology, general practice, health economics, epidemiology, gynaecology), and a consumer and indigenous representative. A working group responsible for quality assurance monitors specified programme outcomes and identifies areas for improvement in laboratory adherence to performance standards and methods to improve quality of Pap smears.

Australia has required formal accreditation of all pathology laboratories since 1987 with three-yearly inspections to ascertain compliance with national standards set by industry and professional authorities (National Pathology Accreditation Advisory Council (NPAAC), 2003). In addition, the screening programme, in consultation with pathology accreditation authorities, has formulated performance standards for technical competence in gynaecological cytology in laboratories; these were voluntary from 1996 and mandatory since 1999. The formal accreditation process requires laboratories to submit standard data, which are compiled in a national report distributed to all laboratories with their own performance data. No individual laboratory is identified in the national

report. The information in these reports is verified against data supplied by the cervical cytology registers. Laboratory performance is self-assessed using in-house quality systems, which set up corrective measures as necessary and report on the process to the assessment authorities. Reimbursement through the national health-care system is unavailable for services in unaccredited laboratories.

The pathology performance standards for Australian laboratories reporting cervical cytology were reviewed in 2003 by NPAAC. Performance measures include the proportion of unsatisfactory and satisfactory specimens, the positive predictive value of a cytology report of a high-grade intraepithelial lesion, the false negative rate among women with histologically confirmed carcinoma *in situ*, and the turnaround time in processing slides. All states have a feedback loop whereby the register supplies laboratories with a performance report on test reporting and laboratories feed information back to the register to allow monitoring of data integrity. Performance indicators, endorsed by the national advisory committee, are reported annually for screening programmes: these include the proportion of women participating by age, the percentage of women with re-screening in the 21 months following a negative screen, the ratio of low- to high-grade abnormalities verified on histology for women aged 20–69 years, the incidence of micro-invasive and all invasive cervical cancers, and mortality. Incidence and mortality by location and mortality in indigenous women is reported every four years (Australian Institute of Health and Welfare, 2003a, b).

New Zealand

A national screening programme came into operation in 1990–91 following recommendations in 1985 for routine cervical screening and the Cartwright

Inquiry that recommended a nationwide population-based programme with central coordination (Skegg *et al.* 1985; Ministry of Health, 1997; National Cervical Screening Programme (NCSP), 2002).

In 1993, enrolment in the programme increased after a legislative change from registration only of those women who consent ('opt-on') to non-registration only of those who specifically refuse ('opt-off'), and histology reporting became compulsory. Maori women's data was protected in 1995 under the Kaitiaki regulations and in 1997, the Ministry of Health established a data management group for Pacific women. Statistical reports were produced in 1993, 1995 and 1998. In 1996–97, a national cervical cytology screening register was centralized in Wellington and in 1998, responsibility for national coordination of the screening programme passed from the Ministry of Health to the Health Funding Authority. Following a review, an additional \$1.4 million was injected into the NCSP during the 1999/2000 year to improve quality standards, set up new independent monitoring processes, improve coordination between providers and improve information for women and training for health educators. The National Screening Team transferred to the Ministry of Health as a separate unit, the National Screening Unit (NSU), within the Public Health Directorate in January 2001.

The NSU funds the screening programme by contracting four independent service providers to provide health promotion to Maori, Pacific and other women in their regions and 12 laboratories (2 public and 10 private) to provide cervical cytology services. Regional screening services are contracted through 13 District Health Boards that provide health promotion and cytology to priority-group women and regional coordination; eight of the

regional services are responsible for local management and data entry of laboratory results to the screening register. In addition, the NSU also funds some low-cost or free cytological and colposcopic services and treatment provided by District Health Boards.

An inquiry into the apparent under-reporting of abnormal results in the Gisborne region found that during the 1990s the NCSP lacked the necessary organization, coordination and some of the constituent parts required for safe and effective screening programmes. A key finding of the inquiry was the need for the Health Act 1956 to be amended to enhance the capacity to monitor, audit and evaluate the NCSP. Appropriate legislation is now before Parliament.

The NCSP Operational Policy and Quality Standards were introduced from November 2000 across the programme. These set standards for laboratory and publicly funded colposcopy services. Since mid 2003, 758 585 women have had one or more screening tests in the NCSP in accordance with the new standards. The national programme sets minimum standards for health services; providers contracted by the Ministry of Health are monitored against these standards. A complete copy of the standards is available on the National Screening Programme website (<http://www.healthywomen.org.nz>).

The screening programme targets all women aged 20–69 who have ever had intercourse for a three-yearly cytological test. In particular, the programme targets women who have never been tested or whose previous test was more than five years ago; these women have a second test after one year. Women who have had a hysterectomy for a benign condition, with complete removal of histologically normal cervical epithelium and a normal cytological history, do not require further screening. Women aged over 40

years and Maori and Pacific women are priority groups in the NCSP.

Pap smears are taken by general medical practitioners (70%), specialists (5%), nurse smear-takers (25%), and two lay smear-takers without a professional background. Cytology reading is funded by the government in 10 community-based and two public hospital-based laboratories. The cost to the woman is only the normal consultation fee, except when the screening unit is directly funding the service, and an additional fee when a liquid-based cytology specimen is used, and private colposcopy services.

Test results are forwarded to the register unless the woman has opted off and does not want the result sent to the programme; results are also sent to the smear-taker. The register sends the woman a reminder when a test is overdue and also supplies the women's cervical screening histories to smear-takers and laboratory cytologists to assist in management decisions. The register also makes sure that the woman is informed of an abnormal result. It holds the name, address, date of birth, smear-taker and their details, cytological and histological history and a record of letters sent to the woman.

Extent of use and access

The programme aims to cover 85% (adjusted for hysterectomy) of all 20–69-year-old women recorded on the screening register in the previous 36 months. In 1998, 76% of eligible women (84% after adjustment for hysterectomy) were tested (Independent Monitoring Group of the National Cervical Screening Programme, 2003). By May 2003, 99.14% of the eligible population (1 084 592 women) were enrolled on the Register (http://www.csi.org.nz/other_reports/NCSPQuestionsnAnswers.htm). Extent of use and access are currently estimated using census data, as the lack

of a population register precludes ready identification of women for targeted recruitment.

The rate of cervical cancer for Maori women in 1997 was nearly three times that of non-Maori (Ministry of Health, 1997). An important function of the screening programme, therefore, is to address the disparities in health outcomes for Maori women. The issue of choice of service provider is important to Maori women. A Maori Women's Cytology Working Group was established and funded. Although Maori smear-takers are not available in all areas, Maori community health initiatives are offered in most areas and a National Kaitiaki Group was formed to act as guardian of registry data (Ministry of Health, 1997).

Performance indicators

National indicators for quantitative monitoring have been developed as part of the process of improving overall quality assurance in the NCSP (National Screening Team, 2000).

An independent monitoring group at the University of Otago is contracted to evaluate the programme against national indicators and targets (Independent Monitoring Group of the National Cervical Screening Programme, 2003). Performance indicators are reported quarterly, six-monthly or annually. The indicators reported quarterly are short-interval re-screening, delayed re-screening for women with a high-grade abnormality, follow-up of women with HSIL cytology, laboratory test reporting, including cytology and histology turnaround time, satisfactory but limited and unsatisfactory smears by laboratory and smear-taker, and the positive predictive value of cytological reports of HSIL.

Annual reporting is required for the numbers of women enrolled, participation, coverage of women having a screening test recorded on the registry in the 36 months preceding the end of

the reporting period, non-participation, re-participation, incidence of cervical cancer and incidence by stage, cervical cancer mortality, rates of cervical abnormality and histology abnormality reporting on the register, interval cancers, programme sensitivity, the opt-off rate, the accuracy of negative cytology reports and residual high-grade disease after treatment (Independent Monitoring Group of the National Cervical Screening Programme, 2003).

Behavioural considerations in screening

Success in delivering a screening programme requires a good understanding of, and attention to, behavioural factors. These factors include communication about cervical cancer and the screening process, the psychological consequences of participating in screening and issues that affect participation. Most research in this area has focused on predictors of attendance at screening and the evaluation of strategies designed to increase participation.

Information and understanding

The cancer screening process can have substantial negative consequences for an individual in terms of anxiety and, if screening results are positive, additional tests and treatment. The psychological consequences of cervical screening are discussed further in Chapter 5.

The fact that screening usually targets individuals who do not have symptoms enhances the significance of potential negative consequences. Women should receive accurate, evidence-based information about both the hazards and the benefits of a screening programme, so that they can make informed decisions about whether to take part (see, for example, General

Medical Council, 1998). While research has identified barriers and deficiencies in information provision, little is known about effective ways of enabling women to make informed decisions (Cockburn *et al.*, 1995; Raffle, 1997; Coulter, 1998; Anderson & Nottingham, 1999). It can be difficult to reconcile the aim of promoting effective forms of health care with that of promoting patient choice and the rights of women who may decide not to be screened (Austoker, 1999).

Knowledge and understanding of cervical cancer

When making a decision about participation in screening, women should ideally take into account their own understanding of cervical cancer and perception of their risk of it, in addition to their understanding of the risks and benefits of screening.

Survey data about knowledge of risk factors for cervical cancer in diverse groups of women has shown a low prevalence of information. HPV testing is increasingly being incorporated in some cervical screening programmes. Knowledge about HPV is, in general, poor. In a survey of female university staff, 70% of respondents (280/400) reported that they had never heard of HPV infection (Pitts & Clarke, 2002). A survey of university students (of whom only 18% had undergone screening due to the age distribution) reported a very similar percentage of 69% (Philips *et al.*, 2003). Among these students, 51% thought that HPV might increase the risk of cervical cancer. In a series of groups of low-income and minority women in the USA, just over half of the participants had heard of HPV, but they greatly overestimated the risk of developing cancer if infected with the virus (Anhang *et al.*, 2004). Implementation of HPV testing in primary screening for cervical cancer would result in a large proportion of women having to be told that they harbour a sexually transmitted viral infec-

tion that can ultimately cause cancer (see Chapter 2). The potential negative impact of imparting this information to the screening public has not been well assessed from a psychological standpoint.

Among Vietnamese migrants to the USA, 52% identified many sexual partners as a risk factor, 49% identified sexual intercourse at an early age and 59%, incorrectly, thought that cervical cancer was familial (Schulmeister & Lifsey, 1999). Another survey reported that 35% of mainly black South African women, all cancer patients and approximately 90% of medical students and student nurses from the same catchment area had some basic knowledge about cervical cancer (Wellensiek *et al.*, 2002). Similar low proportions of women with limited or no knowledge of cervical cancer and risk factors have been reported in Ghana (Adanu, 2002), Botswana (McFarland, 2003), Kenya (Gichangi *et al.*, 2003) and Nigeria (Ayinde & Omigbodun, 2003).

Knowledge and understanding of cervical screening

While some earlier surveys reported poor general knowledge of cervical screening, (Kennedy, 1989; Schwartz *et al.*, 1989; Nicoll *et al.*, 1991; Nugent & Tamlyn-Leaman, 1992; McKie, 1993a, b; Greimel *et al.*, 1997), more recent research indicates an improvement (Eiser & Cole, 2000; Slater, 2000; Eaker *et al.*, 2001a; Marteau *et al.*, 2001; Idestrom *et al.*, 2002; Pitts & Clarke, 2002; Philips *et al.*, 2003). Additional explanations may help communication: the proportion of UK women who understood the implications of a normal result increased from 52% to 70% after an explanation that 'normal' meant that risk was low and not that there was no risk of cancer (Marteau *et al.*, 2001). In a high-resource country (Sweden) where screening is well established, 92% of

survey respondents were aware that cytological testing detects abnormalities in asymptomatic women (Eaker *et al.*, 2001a) and 95% of respondents knew the purpose of screening, although fewer (62%) knew the type of cancer detected by the screening test (Ideström *et al.*, 2002).

Knowledge of the implications of an abnormal test result and the reasons why colposcopy is needed are also not well understood (Nugent & Tamlyn-Leaman, 1992; Onyeka & Martin Hirsch, 2003). As may be expected, understanding was greater among women who had received an abnormal result in the past than among women who had not undergone colposcopy (Pitts & Clarke, 2002); once an abnormality was detected, the perception of personal risk increased (Kavanagh & Broom, 1998).

Bankhead *et al.* (2003) reviewed 49 studies on beliefs and behaviour related to cervical cancer screening, all observational, and found that adherence to follow-up recommendation after a positive test result ranged from 53 to 75%. Several intervention studies have looked at the provision of information to try to reduce anxiety, with the assumption that lower anxiety would result in better adherence to follow-up recommendations, but have found that provision of information increased knowledge without reducing anxiety or increasing attendance at follow-up.

Informed choice about whether or not to attend for cancer screening was explicitly introduced in England in 2001. New mandatory leaflets explaining the benefits and limitations of screening were to accompany every invitation (<http://www.cancerscreening.nhs.uk/news/001.html>). Since this policy and new leaflet were introduced, despite concerns in some areas, no change has been observed in acceptance of screening (Department of Health, Statistical Bulletins for 2001/2,

2002/3, 2003/4, available on <http://www.cancerscreening.nhs.uk/news/001.html>).

Bankhead *et al.* (2003) commented on the relatively poor quality of studies into health behaviour, attitudes and beliefs with regard to cervical cancer screening, although the trend in most observational studies is towards a beneficial effect.

Predictors of attendance for screening

Obtaining the high levels of attendance for screening that are essential to reduce the incidence of cervical cancer has been a major problem in many countries with and without organized screening programmes (Ponten *et al.*, 1995, Lazcano-Ponce *et al.*, 1999a). Besides a high screening coverage of the population at risk, a comprehensive cervical screening programme must also assure maximum return rates among women with abnormal screening results and ensure appropriate care for women requiring follow-up treatment.

Establishing the main determinants of participation is essential to devise effective strategies to increase attendance. These include factors such as the health-care system organization, the socioeconomic level of the population, the costs involved, women's perceptions of vulnerability, anxiety and fear about cervical cancer, beliefs about the relevance of the test, concurrent family difficulties, and the priority accorded to cervical screening (Austoker, 1994). The relative importance of each of these factors will depend on the specific setting.

Studies of predictors of participation published in the last 10 years are presented in Table 56. Studies carried out among specific social or ethnic groups and qualitative studies were not included. Most studies were carried out in developed countries, with only five from developing countries, and most analysed predictors of participation in

cytology-based screening; one analysed determinants of participation in visual inspection-based screening (Sankaranarayan *et al.*, 2003).

Only one of the studies included in Table 56 analysed perceived barriers to screening (Eaker *et al.*, 2001a); it found that time-consuming barriers and economic barriers were associated with non-attendance. The association of emotional barriers was found to be non-significant.

Socio-demographic factors

Age

Most studies have found that younger women are more likely to attend for screening than older women (Calle *et al.*, 1993; Perez-Stable *et al.*, 1995; Mandelblatt *et al.*, 1999a; Hsia *et al.*, 2000; Chan *et al.*, 2002a; Sankaranarayan *et al.*, 2003).

Socioeconomic status

Participation in cervical cancer screening was associated with higher income and educational level in many studies (Calle *et al.*, 1993; Katz & Hofer, 1994; Perez-Stable *et al.*, 1995; Nascimento *et al.*, 1996; Lazcano-Ponce *et al.*, 1997b, 2002; Borrás *et al.*, 1999; Hsia *et al.*, 2000; Maxwell *et al.*, 2001; Chan *et al.*, 2002a; Hewitt *et al.*, 2002; O'Malley *et al.*, 2002, Siahpush & Singh, 2002; Selvin & Brett, 2003). For example, Calle *et al.* (1993) found that 19% of women under the poverty line had never had a screening test compared with only 5.8% of women whose incomes were at least 300% of the poverty level.

Although socioeconomic level may be an important determinant of the ability to pay for preventive services, Katz & Hofer (1994) found that women with higher income and education in the USA and Canada were more likely to have been tested, and that there was no difference between countries, despite Canada's universal health coverage. The authors suggested that

Table 56. Predictors of attending for cervical cancer screening

| Reference | Study type | Country | Study population | Key findings |
|-----------------------------------|---|-------------|--|--|
| Calle <i>et al.</i> (1993) | Population-based cross-sectional study; reported screening | USA | 12 252 women aged 18 and older who participated in the National Health Interview Survey in 1987 | Ever having had a test associated with: <i>Demographic:</i> having been married; white/black background; younger than 65; education > 12 years; income above the poverty line. No difference according to rural residence. |
| Lurie <i>et al.</i> (1993) | Cross-sectional. Women enrolled in a large Mid-western health plan | USA | 24 713 women aged 18 to 75 years old | Having had a test associated with: <i>Health care:</i> having a female physician. |
| Katz & Hofer (1994) | Population-based cross-sectional survey | USA/ Canada | 23 521 and 23 932 women aged 18 and older participating in the 1990 Ontario Health Survey and in the 1990 US National Health Interview Survey respectively | Ever having had a test associated with: <i>Demographic:</i> college degree, higher income, no differences between countries. Disparities persisted when the effect of health insurance was controlled. |
| Majeed <i>et al.</i> (1994) | Cross-sectional/-correlation study. General practice | England | 174 724 women aged 25 to 64 | Having had a test associated with: <i>Demographic:</i> percentage of the practice population under 5 years of age. Overcrowding, age 35–44, and change of address negatively associated with attendance. <i>Health care:</i> female partner. Size of practice and computerization not significant predictors of screening uptake |
| Ronco <i>et al.</i> (1994) | Survey of attenders and non-attenders to a pilot programme in Turin (invitation by GPs) | Italy | 374 (372 analysed) compliers and 513 (398 analysed) non-compliers aged 25–64 years | Attendance increased with: <i>Demographic:</i> older age, lower education level <i>Health care:</i> having had a test more than three years ago. Receiving an invitation with a pre-fixed appointment. <i>Cognitive:</i> Anxiety |
| Bowman <i>et al.</i> (1995) | Prospective study after invitation | Australia | 504 women aged 18–70 from intervention groups | Attendance associated with: <i>Demographic:</i> Younger age, <i>Health care:</i> oral contraception, and receiving a GP letter. <i>Cognitive:</i> perceive screening as necessary |
| Perez-Stable <i>et al.</i> (1995) | Population-based cross-sectional study; reported screening | USA | 1242 Latino and Anglo women aged 35–74 years | Test in the last three years associated with: <i>Demographic:</i> age 35–49; education level > 12 years Ethnicity was not a significant predictor for use of screening in the previous three years |
| Lantz <i>et al.</i> (1997) | Population-based telephone survey | USA | 1168 rural Wisconsin women aged 40 years and older | Having a test in the last three years associated with: <i>Demographic:</i> being married <i>Health care:</i> having health insurance, having a regular physician, having seen a health practitioner in the past year, and having a physician make a recent recommendation for a test The association with income and education was non-significant. Having a hysterectomy and perceiving screening tests to involve physical discomfort were negatively associated. |

Table 56 (contd)

| Reference | Study type | Country | Study population | Key findings |
|-----------------------------------|---|---------|---|--|
| O'Malley <i>et al.</i> (1997) | Population-based cross-sectional study; reported screening | USA | 1420 women aged 18 years and older from four Hispanic groups and three black groups | <i>Health care:</i> Ever and recent screening associated with usual site of care |
| Potosky <i>et al.</i> (1998) | Population-based cross-sectional survey. Reported screening | USA | 9455 women 18 years and older participating in the National Health Interview Survey in 1992 | Screening in the past three years was associated with: <i>Health care:</i> having health insurance. |
| Segnan <i>et al.</i> (1998) | Prospective study after intervention | Italy | 8385 women aged 25–64 years | Higher attendance when age 45–54, married, receiving an invitation from GP, higher education level |
| Borras <i>et al.</i> (1999) | Population-based cross-sectional survey, reported screening | Spain | 5865 women aged 20 years and older participating in the Catalan Health Survey in 1994 | Ever having a test associated with: <i>Demographic:</i> younger age, higher educational level <i>Health care:</i> enrolled in voluntary health insurance |
| Mandelblatt <i>et al.</i> (1999a) | Population-based telephone survey; reported screening | USA | 1420 women aged 18–74 from four Hispanic groups and three black groups in New York city | Ever and recent test associated with: <i>Demographic:</i> younger age, higher education <i>Health care:</i> regular source of care, health insurance <i>Cognitive:</i> positive cancer attitudes |
| Hsia <i>et al.</i> (2000) | Cross-sectional study; reported screening | USA | 55 278 women aged 50–79 participating in the Women's Health Initiative Observational Study in 1994–97 | Test in the last three years associated with: <i>Demographic:</i> younger age, higher education; higher income, married status, ethnic background <i>Health care:</i> usual care provider, medical visit in the past year; health insurance <i>Health status:</i> Presence of some chronic medical conditions, smoking. |
| Eaker <i>et al.</i> (2001a) | Population-based telephone survey; validated reported screening | Sweden | 430 non-attenders and 514 attenders aged 25–59 years. | Attendance associated with (5 years for women 30–59 and 3 years for 25–29 years): <i>Cognitive:</i> perceived satisfactory benefits. <i>Access:</i> time-consuming barriers and economic barriers associated with non-attendance Association between perceived severity of cancer, social support and anxiety non-significant |
| Eaker <i>et al.</i> (2001b) | Population-based telephone survey; validated reported screening | Sweden | 430 non-attenders and 514 attenders aged 25–59 years | Attendance associated with (5 years for women 30–59 and 3 years for 25–29 years): <i>Demographic:</i> living in urban areas. Socioeconomic status was not determinant of participation <i>Health care:</i> oral contraception, visits to a physician 1–5 times/year or less than once a year; seeing the same gynaecologist; having a test on their own initiative <i>Cognitive:</i> Knowing the recommended screening interval |
| Maxwell <i>et al.</i> (2001) | Population-based cross-sectional survey | Canada | 23 287 women aged 25–64 years participating in the National Population Health Survey 1996–1997 | Screening associated with: <i>Demographic:</i> being non-migrant, ever married, higher education, spoken language: English, younger age <i>Health behaviour:</i> having a recent blood pressure check and frequent physical activity <i>Health care:</i> regular physician |

Table 56 (contd)

| Reference | Study type | Country | Study population | Key findings |
|------------------------------------|---|-----------|---|--|
| Coughlin <i>et al.</i> (2002) | Population-based cross-sectional study; reported screening | USA | 131 813 women aged 18 years and older who participated in the Behavioral Risk Factor Surveillance System in 1998–99 | Having had a test in the last three years associated with: <i>Demographic:</i> higher education, higher income, increased level of urbanization, fewer than three persons in the household, being currently married and White/Hispanic/black background. Women aged 30–39 years were more likely to have had a recent test. <i>Health care:</i> health insurance coverage. <i>Health status:</i> having seen a physician in the past year, good or excellent health status, non-smoking and no alcohol consumption. |
| Hewitt <i>et al.</i> (2002) | Population-based cross-sectional study; reported screening | USA | 10 847 women aged 15–44 years who participated in the National Survey of Family Growth in 1995 | Having had a test in the last year associated with: <i>Demographic:</i> family incomes at or above 300% of the poverty level, at least a college degree; not having a non-Hispanic black background. <i>Health care:</i> health insurance. <i>Cervical cancer risk:</i> Having at least one of five risk factors for cervical cancer |
| O'Malley <i>et al.</i> (2002) | Population-based telephone survey; reported screening | USA | 1205 women 40 years and older | Reported receipt of the last two screening tests within the recommended intervals for age: <i>Demographic:</i> higher income <i>Health care:</i> Women under 65: continuity of care, primary care more comprehensive, counselling, patient–physician relationship, trust <i>Older than 64:</i> knowledge about cervical cancer, ever married, continuity of care, counselling, patient–physician relationship |
| Siahpush & Singh (2002) | Population-based cross-sectional study | Australia | 7572 women aged 18–69 years | Ever having a test associated with: <i>Demographic:</i> age 30–49, being married, being born in Australia or New Zealand and high education level. Socio-economic level was not a predictor of participation. |
| Selvin & Brett (2003) | Population-based cross-sectional study; reported screening | USA | 5509 women aged 40–64 years who participated in the 1998 National Health Interview Survey | Test within three years before interview associated with: <i>Demographic:</i> Income above or at 200% of poverty level (except for black women), bachelor's degree or higher <i>Health care:</i> Having a usual source of care; private health insurance <i>Health behaviour:</i> non-smoking except for non-Hispanic black Residential status, self-reported health and marital status not significant predictors of attendance |
| Developing countries | | | | |
| Nascimento <i>et al.</i> (1996) | Population-based cross-sectional survey; reported screening | Brazil | 967 women aged 15–59 years | Ever having had a test associated with: <i>Demographic:</i> older than 24, higher education, higher income, ever married <i>Health care:</i> consulted a physician in the year preceding the survey, oral contraceptive use, and performed breast self-examination |
| Lazcano-Ponce <i>et al.</i> (1997) | Population-based cross-sectional survey; reported screening | Mexico | 4208 women aged 15–49 years from Mexico City or in selected rural areas of the state of Oaxaca | Ever having had a test associated with: <i>Demographic:</i> higher education level; higher socioeconomic level; living in urban areas <i>Health care:</i> access to social security health care <i>Cognitive:</i> knowledge of what the Pap test is used for |

Table 56 (contd)

| Reference | Study type | Country | Study population | Key findings |
|--|--|---------------|---|--|
| Chan <i>et al.</i> (2002) | Population-based cross-sectional survey; reported screening | Hong Kong | 2067 women aged 44–55 years | Test in the previous 12 months associated with: <i>Demographic:</i> Younger age, education level higher than primary level. <i>Health care:</i> receiving hormone treatment; breast self-examination performed <i>Health status:</i> premenopausal status; chronic disease |
| Lazcano-Ponce <i>et al.</i> (2002) | Population-based cross-sectional survey | Mexico | 2094 women aged 15–49 years with a CCSP (National Cervical Cancer Screening Programme) Pap test history | Increased screening associated with: <i>Demographic:</i> higher educational level of the head of the family <i>Health care:</i> history of using two or more family planning methods <i>Cognitive:</i> knowing why the screening test is employed; good experience of screening quality |
| Sankaranarayanan <i>et al.</i> (2003b) | Prospective study of women invited for screening; objective measure of screening | India (rural) | 48 225 women aged 30–59 years | VIA-based screening associated with: <i>Demographic:</i> Younger age, higher educational level, being married, multiparous status and low-income level <i>Health care:</i> having had tubal sterilization for birth control |

factors linked to recruitment and service delivery should also be taken into account in explaining socioeconomic differences. For example, in rural India, women with higher income levels were less likely to participate in the visual-inspection-based screening (Sankaranarayanan *et al.*, 2003). The authors considered that the fact that the screening clinics were organized in public institutions such as health centres or schools might have deterred high-income women from attending.

Marital status

Married, divorced and widowed women were more likely than single women to attend for screening (Calle *et al.*, 1993; Nascimento *et al.*, 1996; Lantz *et al.*, 1997; Segnan *et al.*, 1998; Hsia *et al.*, 2000; Maxwell *et al.*, 2001; Siahpush & Singh, 2002).

Rural residence

Most research suggests that women living in urban areas are more likely to attend for screening (Eaker *et al.*, 2001b; Coughlin *et al.*, 2002).

However, in some European countries, higher participation is seen in rural areas than in large urban centres.

Ethnicity

The evidence on the influence of ethnicity in screening attendance is not conclusive. In the USA, for example, Calle *et al.* (1993) found that women with white or black ethnic background were more likely to be screened and Coughlin *et al.* (2002) found that Hispanic women were as likely as white women to be screened. Perez-Stable *et al.* (1995), in their study comparing Latino and 'Anglo' (non-Latino white) women found no significant effect of ethnicity and Hsia *et al.* (2000) found that only Asian/Pacific islander women were less likely to participate. It is important to note that ethnicity is often a proxy of socioeconomic status, particularly in the USA.

Health status

Some studies have shown that attendance was higher among women with good or excellent health status (Coughlin *et al.*, 2002), while others

have found that women with chronic diseases were more likely to be screened (Chan *et al.*, 2002a). In the USA, Mandelblatt *et al.* (1999a) found that both younger women in poor health and elderly women in good health were more likely to have ever had or to recently have had a test.

Interactions with the health system

Most studies have shown that contacts with the health-care system increase the likelihood of a woman being screened (Lantz *et al.*, 1997; O'Malley *et al.*, 1997; Mandelblatt *et al.*, 1999a; Eaker *et al.*, 2001b; Hsia *et al.*, 2000; Maxwell *et al.*, 2001; Coughlin *et al.*, 2002; Lazcano-Ponce *et al.*, 2002; O'Malley *et al.*, 2002). For example, Maxwell *et al.* (2001) reported that, in Canada, having had a medical consultation in the past year and having a last blood pressure check less than two years ago were important predictors of cervical cancer screening. A contact with the health-care system seems to be one of the main determinants of attendance also in developing

countries (Nascimento *et al.*, 1996; Sankaranarayanan *et al.*, 2003b). For example, in India, both a greater number of children and use of family planning methods were associated with higher participation (Sankaranarayanan *et al.*, 2003b). A previous contact with gynaecological and maternal services may increase awareness about gynaecological procedures and encourage further contacts with health-care services, making women more responsive to screening. Having a regular source of care was also linked to higher attendance in many studies (Lantz *et al.*, 1997; Mandelblatt *et al.*, 1999a; Eaker *et al.*, 2001b; Maxwell *et al.*, 2001; O'Malley *et al.*, 2002). Indeed, Lantz *et al.* (1997) found that having a regular source of care was a main predictor of screening, even after controlling for other health-care access factors such as health insurance.

Aspects related to the patient-physician relationship and contact with the health-care system appear to be important determinants of attendance. The probability of attending screening was higher in women who reported good experiences with the health system. For example, O'Malley *et al.* (2002) reported that women who evaluated primary care as more comprehensive, and their relation with their physician based on trust, were also more likely to be screened. In Mexico, women with good previous screening experiences were four times more likely to be re-screened (Lazcano-Ponce *et al.*, 2002). In El Salvador, a pilot study that implemented a quality-improvement process resulted in screening 25% of women aged 30–59 years who had never been screened. Another qualitative study summarizing the experiences of research projects in Bolivia, Peru, Kenya, South Africa, and Mexico carried out by the Alliance for Cervical Cancer Prevention (ACCP) reported that women expressed the need for confidentiality and privacy.

Women commonly report feeling ashamed, especially when privacy is lacking or when male providers perform the examination (Bingham *et al.*, 2003).

The effect of the gender of the physician was examined in two studies and in both it appeared that women having a female physician were more likely to be screened (Lurie *et al.* 1993; Majeed *et al.*, 1994). A recommendation by a doctor to attend screening also appeared to have an important influence on women's decision to be screened (Bowman *et al.*, 1995; Lantz *et al.*, 1997; Segnan *et al.*, 1998). For example, in the USA, women who received a physician's recommendation for screening were 2.3 times more likely to be screened (Lantz *et al.*, 1997). Ronco *et al.* (1994) reported that if the recommendation included a fixed appointment, women were more likely to attend than if the invitation did not.

Among the factors related to access to health care, health insurance appears to be one of the most important predictors of screening, as most studies have found that having health insurance increased the likelihood of participation (Katz & Hofer, 1994; Lantz *et al.*, 1997; Potosky *et al.*, 1998; Borrás *et al.*, 1999; Lazcano-Ponce *et al.*, 1997b; Hsia *et al.*, 2000; Selvin & Brett, 2003; Hewitt *et al.*, 2002). There is limited evidence related to other access factors such as distance to a health-care centre and cost of transport. The introduction of mobile clinics in rural Thailand increased participation in a cytology-based screening from 21 to 57% (Swaddiwudhipong *et al.*, 1995, 1999).

Knowledge and attitudes as predictors of attendance

Knowledge of screening

All of the studies included in Table 56 that analysed the effect of knowledge (Bowman *et al.*, 1995; Mandelblatt *et al.*, 1999a; Eaker *et al.* 2001b;

Lazcano-Ponce *et al.*, 1997b, 2002; O'Malley *et al.*, 2002) found that knowledge about the screening test increased the probability of screening. For example, in Mexico, women who knew why the test was given were three times more likely to be screened (Lazcano-Ponce *et al.*, 2002). In Sweden, knowing the recommended screening interval increased the probability of attendance (Eaker *et al.*, 2001b). Also, women are more likely to attend screening if they perceive screening as necessary or beneficial (Bowman *et al.*, 1995; Eaker *et al.*, 2001a). There is no evidence that awareness of risk influences women's decisions on whether to be screened.

Fear/anxiety

In most studies, increased anxiety was associated with lower probability of women attending for screening. In Italy, Ronco *et al.* (1994) found that anxiety caused by periodic controls was an important negative determinant of compliance. In the USA, positive attitudes to cancer (less anxiety and hopelessness and a lower level of denial) were key determinants of participation (Mandelblatt *et al.*, 1999a). Extensive qualitative research on reasons for non-attendance indicates that both fear of cancer and anxiety and knowledge of screening are key barriers to screening. A recent in-depth qualitative analysis in five Latin American countries indicated 'fear of cancer' as an underlying reason for women not to seek screening services (Agurto *et al.*, 2004). The authors suggest that this aspect is articulated by women in different forms, such as poor knowledge and understanding or not having time, depending on the questions of the survey; but when women are prompted to explain further they consistently alluded to 'fear of cancer'.

Strategies to encourage participation in cervical cancer screening programmes

Many approaches to increase participation in screening have been analysed (Table 57). Studies differ in the populations addressed, the settings where they were implemented and the methods used to test the approach. Even when two studies test the same strategy, for example, an invitation by letter, it is not possible to control for all the variables that may have an influence on women's participation, such as the style and tone of the letter, the actual service being offered, who signs the letter and so on. In general, limited information is available about these methodological differences, but it is clear that apparently similar approaches can differ in various aspects that might affect participation.

The effectiveness of a strategy will depend on how the health system is organized; thus, an invitation letter may be effective if the service is provided free of charge, but may not be in certain settings if women have to pay for the test.

The types of intervention that have been investigated include strategies targeting individual women, health-care providers and communities.

Strategies targeting individual women

Invitation letters

Of the 29 studies presented in Table 57, 15 evaluated the effectiveness of invitation letters compared with a control group with no intervention (McDowell *et al.*, 1989; Pierce *et al.*, 1989; Clementz *et al.*, 1990; Ornstein *et al.*, 1991; Lancaster & Elton, 1992; Bowman *et al.*, 1995; Lantz *et al.*, 1995; Pritchard *et al.*, 1995; Binstock *et al.*, 1997; Buehler & Parsons, 1997; Somkin *et al.*, 1997; Burack *et al.*, 1998; Del Mar *et al.*, 1998; Torres Mejia *et al.*, 2000; Vogt *et al.*, 2003). Invitation letters significantly increased screening uptake in 10 of these studies. Two studies found a non-signifi-

cantly better participation in the control group (Clementz *et al.*, 1990; Del Mar *et al.*, 1998). In the one by Clementz *et al.* (1990), subjects were offered up to seven other screening tests in the same letter (including faecal occult blood test, digital rectal examination, sigmoidoscopy, pelvic bimanual examination, breast examination and mammography), so it is difficult to draw conclusions related only to cervical cancer screening, as the reasons for low attendance may be related to how patients react when invited for several screening tests. Additional evidence from programme evaluations (not included in Table 57) confirms the importance of the invitation letter. For example, a screening programme in Denmark issued personal invitations to target women over a period of 15 years. The participation among women aged 30–50 was 91% (Lyng *et al.*, 1992). After that, personal invitations were stopped and participation in the same age group dropped to 66%.

The context of the trial and the characteristics of the letter varied across the studies in Table 57. For example, in two studies (Burack *et al.*, 1998; Vogt *et al.*, 2003), the letters were accompanied by educational brochures. In six studies, letters were followed by mailed or phone reminders (McDowell *et al.*, 1989; Ornstein *et al.*, 1991; Lantz *et al.*, 1995; Buehler & Parsons, 1997; Torres Mejia *et al.*, 2000; Vogt *et al.*, 2003). In the study by Vogt *et al.* (2003), the increase in attendance was significant only when the letter was followed by a phone reminder; a letter followed by a mailed reminder led to no significant increase.

The two studies that analysed the effect of sending a letter to minority group women found no effect of the intervention (Del Mar *et al.*, 1998; Hunt *et al.*, 1998). However, in one of these (Del Mar *et al.*, 1998), the letter followed a media campaign introduced two months before in the whole region,

so an effect of contamination between the intervention and control groups cannot be eliminated.

The only study conducted in a developing country found significantly higher participation among women who received an invitation letter (Torres Mejia *et al.*, 2000). The project was carried out in the context of the Mexican Social Security Institute, which provides medical services for nearly 60% of the Mexican population. In the total group of women invited, the effectiveness of the intervention was 20.1% versus 3.3% in the control group. However, it may be difficult to adopt this strategy in other developing countries due to the lack of mailing lists, ineffective or inexistent postal systems and women's difficulties in reading or understanding letters.

Two studies used invitation letters signed by different authority sources. Significantly better participation was observed in the intervention groups receiving letters signed by GPs versus letters signed by female nurse practitioners (Bowman *et al.*, 1995) or by programme coordinators (Segnan *et al.*, 1998).

Three studies explored the effect of including a fixed appointment in the letter versus an open invitation to make an appointment (Wilson & Leeming, 1987; Pritchard *et al.*, 1995; Segnan *et al.*, 1998); all found a favourable effect of a fixed appointment. For example, in Italy, the overall compliance with screening was 36.1% when the letter signed by the GP included a fixed appointment, but 22.7% when it only included a prompting to contact the screening centre to make an appointment (Segnan *et al.*, 1998).

In three studies, invitation letters were compared with phone invitations. Binstock *et al.* (1997) found that telephone invitations were more effective, whereas in the study by McDowell *et al.* (1989) invitation letters were more effective. However, the latter study included a reminder 21 days later if the

Table 57. Studies evaluating interventions to increase cervical cancer screening attendance

| Reference | Study type | Country | Study population | Key findings |
|------------------------------------|--|--|--|---|
| Wilson & Leeming (1987), UK | Screening uptake | National Screening Programme; women aged 45–65 years with no record of having a previous smear | a. Letter of invitation to make an appointment + two reminders, $N = 125$ (122 analysed) b. Letter with an appointment date + two reminders. $N = 125$ (118 analysed) | a. 32% b. 47% Significant differences |
| McDowell <i>et al.</i> (1989), USA | Test during study year | Hospital; no test in past year | a. GP letter and reminder letter after 21 days. $N = 367$ b. Physician reminder. $N = 332$ c. Telephone call. $N = 377$ d. Control group. $N = 330$ | a. 25.9% b. 16.1% c. 20% d. 13.7% Significant increase only for the GP letter |
| Pierce <i>et al.</i> (1989), UK | Test during study year | General practice; women registered with a general practice eligible for a test | a. Letter asking women to have a smear. $N = 140$ b. Physician reminder. $N = 142$ c. Control group. $N = 134$ | a. 32%* b. 27%* c. 15% * $p < 0.01$ Differences between intervention groups NS |
| Robson <i>et al.</i> (1989), UK | Test within preceding three years | General practice | a. Patients had open access to health promotion nurse and had their risk factors assessed and followed up by both their GP and the nurse. $N = 799$ b. Control, usual care (i.e. managed by GP alone). $N = 806$ | a. 76% b. 49% $p < 0.001$ |
| Clementz <i>et al.</i> (1990), USA | Test up to four months after the intervention | Female patients attending ambulatory clinic; aged 50–69 years | a. Personalized GP's letter, one month before due date of tests with an educational component. $N = 102$ b. Control group received usual care (not described). $N = 76$ | a. 20.6% b. 30.3% NS differences |
| McAvoy & Raza (1991), UK | Test within four months after the intervention | National screening programme; Asian women resident in Leicester, aged 18–52 years with no record of having had a test | a. Home visit and a multilingual video. $N = 263$ b. Home visit, multilingual leaflet and fact sheet. $N = 219$ c. Posted multilingual leaflet and fact sheet. $N = 131$ d. Control group received no intervention. $N = 124$ | a. 30%* b. 26%* c. 11%# d. 5% *Difference with control group significant #Difference with control group NS |
| Ornstein <i>et al.</i> (1991), USA | Screening uptake | Family medicine clinic; women aged 18 years and over; not screened in previous 2 years; active patient of the family medicine centre (i.e. had visited clinic in previous 2 years) | a. Physicians received computerized reminders. $N = 1988$ participants; 14 physicians b. Participants were sent and invitation to attend followed by another personalized reminder letter (6 months later). $N = 1925$ participants, 12 physicians c. Both physicians and participant reminders. $N = 1908$ participants, 13 physicians d. Control group, no intervention. $N = 1576$ participants, 10 physicians | Slight decline in intervention group. |

Table 57 (contd)

| Reference | Study type | Country | Study population | Key findings |
|---|---|--|--|---|
| Ward <i>et al.</i> (1991), Australia | Test up to one month after the initial consultation | General practice; women aged 20–65 years; provided consent | a. Minimal intervention: GP advised eligible women of need for test and offered to perform it immediately. Those not consenting advised to make appointment for test within a week. <i>N</i> = 99 b. Maximal intervention: GP advised women of need for test and offered to perform it immediately; GP attempted to persuade those not consenting during that consultation by exploring barriers and reasons for self-exclusions. If still did not consent, GP advised making an appointment for test within a week. <i>N</i> = 103 | a. 55% b. 67% NS differences. |
| Lancaster & Elton (1992), UK | Test during a six week period | General practice; women aged 50–64 years; resident in study area | a. Cervical screening invitation sent with breast screening invitation. <i>N</i> = 474 b. Breast screening invitation only sent (control). <i>N</i> = 483 | a. 28% b. 13% <i>p</i> < 0.001 |
| Bowman <i>et al.</i> (1995), Australia | Screening uptake at six months after the intervention | Community and general practice. Women aged 18–70 years who reported ever having sexual intercourse and who had not had a test in the previous three years if a complete set of information was available | a. GP reminder letter. <i>N</i> = 220 (178 analysed) b. Women's health clinic invitation for screening by a female nurse practitioner. <i>N</i> = 220 (164 analysed) c. Mailed educational pamphlet personally addressed to women. <i>N</i> = 219 (162 analysed) d. Control group (not stated) <i>N</i> = 219 (155 analysed). Note: analysis carried out on women who responded to the follow-up survey | a. 36.9% b. 22.6% c. 25.9% d. 24.5% Letter from the general practitioner significantly increased pap smear uptake. Differences between other groups and control group NS. |
| Lantz <i>et al.</i> (1995), USA | Screening uptake 6 months after the intervention | Community health centre; women aged 40–79 years, enrolled in benefit scheme' no claim for Pap test in past 3 years | a. Reminder letter from primary-care physician for test(s) required. Follow-up phone call/letter from a health educator (nurse or social work intern) 7–10 days later, to offer barrier counselling and/or assistance with appointment making. <i>N</i> = 337 b. Control group received 'usual care' (not described). <i>N</i> = 322 | a. 19% b. 6% [values recalculated from original data] Significant difference |
| Pritchard <i>et al.</i> (1995), Australia | Test within 12 months of entry into the study | General practice; women aged 36–69 years at a university general practice in a socio-economically disadvantaged area of Perth | a. Physician reminder (tagged notes). <i>N</i> = 198 b. Letter with invitation to make an appointment. <i>N</i> = 206 c. Letter with fixed appointment. <i>N</i> = 168 d. Control group (usual care). <i>N</i> = 185 | a. 21.2%* b. 25.7%# c. 30.4%# d. 16.8% *NS difference with the control group # Difference with the control group statistically significant. |
| Yancey <i>et al.</i> (1995), USA | Test within 5 months after the intervention | Health clinic; women attending one of the two study clinics. | a. Culturally sensitive health education videos dealing with breast and cervical cancer played in waiting room. <i>N</i> = 868 b. Control, no intervention. <i>N</i> = 876 | a. 19.4% b. 13.7 % <i>p</i> < 0.05 . |

Table 57 (contd)

| Reference | Study type | Country | Study population | Key findings |
|------------------------------------|--|--|---|--|
| Binstock <i>et al.</i> (1997), USA | Screening uptake at 12 months after intervention | Health maintenance organization. Women aged 25–49 years, enrolled for three years at the Kaiser Permanente Health Plan who were likely to seek out-patient care at one of the three medical centres | a. Telephone call. <i>N</i> = 1526 b. Letter. <i>N</i> = 1526 c. Memo to woman's primary provider. <i>N</i> = 1526 d. Chart reminder affixed to outside of woman's medical record. <i>N</i> = 1526 e. No intervention (control group). <i>N</i> = 1526 | a. 35.1% b. 26.4% c. 25.5% d. 23.9% e. 16.3% Differences with control group significant for all groups. <i>p</i> < 0.001 No significant differences between b, c and d |
| Buehler & Parsons (1997), Canada | Screening uptake at 6 months after intervention | Family medicine clinic. Patients of the clinics aged 18–69 years who had not had a test in the previous three years | a. Personal letter and reminder letter 4 weeks later (letter head of the provincial cytology registry signed by co-investigators). <i>N</i> = 178 b. Control group not received letter. <i>N</i> = 208 | a. 10.7% b. 6.3% NS differences |
| Somkin <i>et al.</i> (1997), USA | Test in the six months following the intervention | Health maintenance organization (HMO); women aged 20–64 years, no test in previous 36 months; residents of study area; continuously enrolled as a member of HMO for the previous 36 months | a. Letter signed by a physician inviting women to make an appointment. <i>N</i> = 1188 b. Letter signed by a physician inviting women to make an appointment and chart. Providers encouraged by presentations by researchers and memoranda describing the project. <i>N</i> = 1188 c. Usual care (required a referral from a physician). <i>N</i> = 1188. | a. 19.4%* b. 22.8%* c. 9.1% Difference with control group significant. <i>p</i> < 0.01 |
| Sung <i>et al.</i> (1997) | Test up to six months after completion of the intervention | Community; African American women; aged 18 years and older | a. Lay health workers visited women three times to provide a culturally sensitive educational programme emphasizing need for screening through printed material and video. <i>N</i> = 163 b. Control group received educational information on completion of follow-up | No significant increase |
| Burack <i>et al.</i> (1998), USA | Screening uptake during the study year | Health maintenance organization (HMO); Age 18–40 years; HMO member; visited one of the primary care study sites in the previous years; had not had a test in the previous year. | a. Patient reminder (invitation letter signed by the HMO director) + National Cancer Institute educational brochure. <i>N</i> = 964 b. Reminder for physician. <i>N</i> = 960 c. Reminders for both physician and participants. <i>N</i> = 960 d. Control (no reminder). <i>N</i> = 964 | a. 29% b. 29% c. 32% d. 28% Differences with control group NS |
| Margolis <i>et al.</i> (1998), USA | Screening uptake 1 year after the intervention | Community health centre; women aged 40 years and over attending appointments in the clinics; had not had a test in the previous year. | a. Lay health workers assessed screening status and offered women screening with a female nurse practitioner. <i>N</i> = 566 (470 analysed) b. Usual care group. <i>N</i> = 536 (437 analysed) | a. 63.2% b. 50.3% <i>p</i> < 0.002 |

Table 57 (contd)

| Reference | Study type | Country | Study population | Key findings |
|---|--|---|--|---|
| Segnan <i>et al.</i> (1998), Italy | Screening uptake at 12 months after the initial invitation | General practice in national screening programme; women aged 25–64 years; resident of Turin | a. Personal letter signed by GP with prefixed appointment (control). <i>N</i> = 2100 b. Personal letter, signed GP with open-ended appointment. <i>N</i> = 2093 c. Personal letter signed by programme coordinator with prefixed appointment. <i>N</i> = 2094 d. Personal letter with extended text signed by GP with prefixed appointment. <i>N</i> = 2098 | a. 36.1% b. 22.7%* c. 30.9%* d. 36.7% Personal invitation letters signed by the GP with prefixed appointments induced a significant increase in compliance with screening. <i>p</i> value not provided * Significant difference with group (a) |
| Rimer <i>et al.</i> (1999), USA | Screening uptake 16 months after the intervention | Community health centre, women aged 18 years or over; client of medical centre who had visited centre in previous 18 months (care for black, low income, low education population), had not had a test in the last year | a. Provider prompting intervention only. <i>N</i> = 202 b. Provider prompting and tailored educational print communications (Healthy Birthday cards) <i>N</i> = 204 c. Provider prompting, tailored educational print communications and tailored telephone counselling. <i>N</i> = 213 | a. 56% b. 52% c. 64% Provider prompting, tailored educational print communications and tailored telephone counselling induced increased compliance, <i>p</i> = 0.05 |
| Allen <i>et al.</i> (2001), USA | Screening uptake within past three years | Worksite; women 40 years and older who were employed for more than 15 hours per week on a permanent basis | a. Intervention sites: Voluntary advisory boards with worker participation; peer health advisors (PHA); group sessions led by PHAs; one-to-one outreach activities, worksite-wide health education; other events. <i>N</i> = 1489 b. Control sites: no specific activities. <i>N</i> = 1308 | a. 89.9% b. 87.7% Significant difference \ |
| Vogt <i>et al.</i> (2003), USA | Test within 12 weeks after the intervention | Health-care organization; women aged 18–70 who had at least 3 years of continuous membership before the study who had not received a test during the same 3-year period | a. Letter from the programme and brochure followed by a second letter to women who had not had an examination six weeks later after the first contact. <i>N</i> = 206 b. Letter as in the first group followed by a phone call to all those not screened in the first six weeks. <i>N</i> = 113 c. Phone call followed by a second phone call to all those not screened in the first six weeks. <i>N</i> = 88 d. Usual care. <i>N</i> = 280 | a. 22%* b. 54%# c. 50%# d. 17% # <i>p</i> < 0.0001 * <i>p</i> = 0.16 Interventions were more effective than usual care except for the letter/letter only intervention. Letter with phone was as effective as phone/phone outreach |
| Del Mar <i>et al.</i> (1998), Australia | Screening uptake one year after the intervention | Community; women aged 18–67 years; Vietnamese | a. Personal letter in Vietnamese informing them about screening and its benefits. <i>N</i> = 359 b. Control group did not receive a letter. <i>N</i> = 330 | a. 10% b. 12% NS differences |

Table 57 (contd)

| Reference | Study type | Country | Study population | Key findings |
|---|---|---|---|--|
| Minority groups | | | | |
| Navarro <i>et al.</i> (1998), USA | Screening uptake 3 months after the intervention | Latino community, 18 years and older | a. Por La Vida (PLV) programme with community workers (<i>consejeras</i>) taking 12 weekly educational sessions with the groups of women. <i>N</i> = 274; analysed 199 b. Control, no PLV programme; instead <i>consejeras</i> participated in a community living skills programme. <i>N</i> = 238; analysed 162 | a. 65.3% b. 61.1% NS differences Differences in increase between the control and the intervention NS |
| Hunt <i>et al.</i> (1998), Australia | Screening uptake three months after the intervention | Community health centre; aboriginal women seen more than twice in the past three years and had no record of hysterectomy, had not had a test in the last 3 years | a. Personal approach. Women approached by aboriginal health workers and invited for screening. <i>N</i> = 119 b. Letter. Designed by aboriginal workers stating individual overdue for test and inviting them to attend. <i>N</i> = 125 c. Control. Usual care with reminder tags for clinic staff attached to medical records. <i>N</i> = 122 | a. 6.7% b. 2.4% c. 0 NS differences. |
| Taylor <i>et al.</i> (2002a), USA | Screening uptake | Community; Chinese women 20–69 years of age; spoke Cantonese, Mandarin or English, had no history of invasive cervical cancer and were under-utilizers of screening | a. Culturally appropriate outreach worker intervention. Health education, video, motivational pamphlet, educational brochure and a fact sheet. Home visits, tailored counselling by outreach workers. <i>N</i> = 161; analysed = 129 b. Direct mail with a cover letter, the education video, motivational pamphlet, educational brochure and fact sheet. <i>N</i> = 161; analysed = 139 | a. 39% b. 25% c. 15% a versus c, <i>p</i> < 0.001 b versus c, <i>p</i> = 0.03 a versus b, <i>p</i> = 0.02 |
| Taylor <i>et al.</i> (2002), USA | Screening uptake in the last twelve months. | Community; Cambodian refugees in Seattle; women aged 18 and older | c. Control: usual care. <i>N</i> = 160; analysed = 134 a. Introductory mailing, home visit including educational video and tailored counselling; group meetings. <i>N</i> = 144 b. Control: usual care. <i>N</i> = 145 | a. 61% b. 62% NS differences |
| Developing countries | | | | |
| Torres Mejia <i>et al.</i> (2000), Mexico | Screening uptake up to 8.5 weeks after the intervention | Mexican Social Security Clinics (Morelos). Women 20–64 years who had not had a test in the previous 12 months | a. Intervention: Letter of invitation and reminder. <i>N</i> = 2119 b. Control group not received letter. <i>N</i> = 2100 | a. 20.1% b. 3.3% Significant differences |

women did not respond to the first letter, whereas in the former no reminder was sent after the phone call. When a phone call was followed by a second phone call to all women not screened in the first six weeks, it was more effective than a letter followed by a mailed reminder (Vogt *et al.*, 2003). These three studies also compared an invitation phone call and no intervention. In all three studies, the uptake of screening was higher in the phone call group, but not significantly in the study by Binstock *et al.* (1997). In the study by Vogt *et al.* (2003) the phone–phone approach was as effective as a letter–phone approach. However, the letter followed by a phone call was the most cost-effective approach. It was estimated that the phone–phone approach produced one additional screening for \$305 versus \$185 with the letter–phone approach.

Personal approach

The efficacy of a personal contact was evaluated in six studies (McAvoy & Raza, 1991; Sung *et al.*, 1997; Hunt *et al.*, 1998; Margolis *et al.*, 1998; Taylor *et al.*, 2002a, b). The face-to-face approach significantly increased screening uptake in three of them (McAvoy & Raza, 1991; Margolis *et al.*, 1998; Taylor *et al.*, 2002a). However, the conditions under which the personal contact took place varied enormously from study to study. In the study by Margolis *et al.* (1998), lay health workers approached women attending a community health centre and offered screening with a female nurse practitioner. The effectiveness of this approach was evaluated in relation to usual care; 63.2% of the invited women complied with screening versus 50.3% in the control group. However, 36% of randomized women cancelled or missed appointments, so they were not contacted at all and were not included in the final analysis. With a strategy based on approaching

women attending a health centre, non-users will never be reached. Taylor *et al.* (2002a) evaluated home visits that included delivering educational material (a health education video, a motivational pamphlet, an educational brochure and fact sheet) and providing tailored counselling, in comparison with only mailing the educational material and with a control group receiving usual care. The first approach was the most effective in increasing participation rates. However, no data on costs were provided; as up to ten attempts were made to contact each woman in the first group, it would presumably have been the most expensive.

Educational interventions

Ten studies evaluated different types of educational intervention including printed material (Rimer *et al.*, 1999; Bowman *et al.*, 1995), video/slide presentations (Yancey *et al.*, 1995), face-to-face contacts (Navarro *et al.*, 1998; Allen *et al.*, 2001) or combinations of various educational approaches (Taylor *et al.*, 2002a, b; McAvoy & Raza, 1991; Sung *et al.*, 1997). Mailed printed materials do not appear to increase uptake of screening. For example, in Australia, Bowman *et al.* (1995) found that mailed educational pamphlets personally addressed to women did not increase uptake compared with a letter from the GP without the educational pamphlet or a control group (no intervention). Educational video tapes were found to be effective compared with no intervention, both when mailed (Taylor *et al.*, 2002a) and when played in a health-care setting. For example, video presentations played in the waiting room of health clinics increased uptake of screening among women attending the clinics in the USA by around 30% (Yancey *et al.*, 1995). The effectiveness of face-to-face educational interventions seems to be low, as no (Navarro *et al.*, 1998) or modest (Allen *et al.*, 2001) effect was found in the two stud-

ies included. However, the face-to-face approaches differed greatly. Navarro *et al.* (1998) compared the effect of 12 educational sessions on cervical cancer screening with the effect of 12 educational sessions about living in the community. Allen *et al.* (2001) invited women to a group meeting carried out in their workplace. Multi-component interventions seemed to be the most effective approach (Allen *et al.*, 2001; Taylor *et al.*, 2002a). For example, Allen *et al.* (2001) found that health education provided in workplaces together with worker participation, group sessions and one-to-one outreach activities significantly increased the uptake of screening.

Counselling, with exploration of possible barriers to screening and reasons for self-exclusion, to persuade the woman to have screening was analysed in three studies. In the USA, Rimer *et al.* (1999) found that complementing the physician's reminder and mailed tailored educational print communication with tailored telephone counselling increased participation. Attendance was increased in a general practice setting in the United Kingdom if patients had access to a health promotion nurse and had their risk factors assessed and followed up by both the GP and the nurse (Robson *et al.*, 1989). In contrast, Ward *et al.* (1991) found no significant difference in Australia between a minimal intervention by which GPs advised eligible women to be screened and a maximal intervention during which they also attempted to provide counselling. However, since the average time spent on counselling was only 91 seconds (range 6 seconds to 3 minutes and 44 seconds), it is impossible to determine whether counselling was really ineffective or if insufficient time was allocated to perform it effectively.

Strategies targeting health-care providers

Despite the recognized influential role of doctors in promoting screening,

many women still report that their doctor failed to recommend screening. Seven of the studies included in Table 57 evaluated the effect of several types of physician reminder (including a flag reminder affixed to the woman's medical record) versus a control group with no intervention (Binstock *et al.*, 1997; Burack *et al.*, 1998; McDowell *et al.*, 1989; Ornstein *et al.*, 1991; Pritchard *et al.*, 1995; Pierce *et al.*, 1989; Somkin *et al.*, 1997). Only two of these studies found a significant increase in screening uptake compared with no intervention (Binstock *et al.*, 1997; Pierce *et al.*, 1989). However, no differences were found between the physician reminders and other types of intervention measured in these two studies (i.e., telephone or mailed invitations sent to women).

In the United Kingdom, target payments for GPs have been linked to the level of coverage achieved, with the payment for coverage of 80% or over being almost four times that for 50% to 79%. Introduction of such payments led to a dramatic improvement in coverage, from less than 40% to over 80% (Patnick, 2000; NHS 2003a, b).

Community strategies

Mass media campaigns

The impact of mass media campaigns in increasing attendance in cervical cancer screening was summarized in a review of different strategies by Black *et al.* (2002). Studies included in this review showed that mass media campaigns combined with other strategies were effective at increasing either screening rates or early cancer detection. Of the four studies reviewed that used mass media campaigns alone (Suarez *et al.*, 1993a, b; Mitchell *et al.*, 1997; Suarez *et al.*, 1997), only one was effective, in a specific subpopulation targeted with language-specific materiel (Mitchell *et al.*, 1997). Shelley *et al.*, (1991) reported an increased attendance in New South Wales, Australia, after a mass media

campaign including television and radio commercials, advertisements in two women's magazines and posters and pamphlets distributed to GPs.

Involving family and community members

For many women, particularly those of ethnic or minority groups in developed countries and women in developing countries, their decision about cervical cancer screening will be greatly influenced by the husband or other key family and community members (Lazcano-Ponce *et al.*, 2002). Involving family and community members has been proposed as an important strategy to increase attendance in screening programmes. However, there is limited evidence on the effectiveness of this approach. In a randomized controlled trial carried out in rural India to evaluate the effectiveness of VIA (Sankaranarayanan *et al.*, 2003b), the main components of the project included health education activities, personal invitations, mobile clinics and involving key members and leaders of the community. Attendance reached 63.4%, which represents a reasonable level considering that no women had ever been tested previously in the region.

Strategies to improve follow-up after an abnormal test result

Obtaining good levels of attendance for screening is a necessary but insufficient condition for effectiveness of a cervical cancer screening programme. Screened women with abnormal tests must also receive follow-up and appropriate treatment. Rates of incomplete follow-up vary enormously across settings and populations; between 7 and 49% of women with abnormal test results fail to receive adequate follow-up (Yabroff *et al.*, 2000) and a study in the Amazonian region of Peru found that only 25% of women with abnormal cytology received appropriate follow-up care (Gage *et al.*, 2003). Despite the importance of assuring good levels of compliance with fol-

low-up, most efforts have focused on increasing attendance in screening programmes. For example, in a Cochrane Review of strategies to increase attendance at cervical cancer screening (Forbes *et al.*, 2004), only three of the selected 35 studies were about compliance with follow-up.

A notification letter including some educational material was evaluated in two studies (Paskett *et al.*, 1990; Marcus *et al.*, 1992). Adding educational materials to the notification letter did not have a significant impact on the uptake of follow-up visits in any of these studies except in the group that also received an educational slide-tape programme (Marcus *et al.*, 1992). In this study, providing transportation incentives increased the odds of follow-up compared with women receiving usual care, but the effect was lower than that obtained with the letter plus slide-tape programme. A combination of computerized tracking of follow-up, transportation and financial incentives yielded only a limited increase in the intervention group in relation to the control group (Kaplan *et al.*, 2000). An invitation to consult a nurse who presented educational information about abnormal tests did not result in a significant difference between the groups (Peters *et al.*, 1999).

Although educational interventions have been shown to improve women's knowledge about the meaning of an abnormal test result, whether this improved knowledge correlates with lower anxiety or improved adherence for follow-up is unclear (Zeisler *et al.*, 1997; Fylan, 1998).

Studies using alternative screening approaches

Alternative methods are being evaluated to provide simple and low-cost screening in developing countries where organizing a cytology-based programme is not feasible (Sankaranarayanan *et al.*, 2001). Combining testing with an immediate offer of treat-

ment for screen-positive women has been shown to be a feasible option in low-resource settings (Gaffikin *et al.*, 2003). One advantage of the "see-and-treat" or "screen-and-treat" approaches is that they reduce the need for follow-up visits and thus decrease the proba-

bility of loss to follow-up. Several recent studies have evaluated compliance with treatment using this approach. For example, in a VIA-based demonstration project in rural Thailand, nearly 93% of screen-positive women received cryotherapy in a "screen-and-

treat" scheme (Gaffikin *et al.*, 2003). In India, compliance with treatment for high-grade lesions was 74%; in this study, cryotherapy was offered on a "see-and-treat" basis and LEEP was provided through referral to a hospital (Sankaranarayanan *et al.*, 2003b).