TARGETS

The report assumes adoption of the targets for cervical cancer screening outlined in Health for All Australians. These are:

- to increase triennial participation in Pap smear screening to 50 percent or more of women aged 20-69 years by the year 1990, to 75 percent or more by the year 1995 and to all but a negligible number by the year 2000;
- to establish organised population based cervical neoplasia screening programs in each State and Territory by the year 1990.

Outcome targets would include participation rates, disaggregated for newly recruited women and recalls.

Process targets would focus on significant milestones in setting up elements of the screening pathway.

These intermediate targets are indicators en route to the ultimate objective of cervical cancer screening; the reduction in premature deaths from cervical cancer to 10 percent or less of the potential lives lost in the absence of screening.

ADMINISTRATION/CO-ORDINATION

State/Territory units play a key role in planning, co-ordination and administration of regional and local cervical cancer screening programs and support services. Their functions may vary between jurisdictions, depending on the roles allocated to non-government organisations such as the Family Planning Association and the presence of cervical cytology registries.

The views of States/Territories are sought on the most appropriate administration and co-ordination structures for their jurisdictions.

ROLE OF CERVICAL CYTOLOGY AND CANCER REGISTRIES

Features of an organised approach to cervical cancer screening that are more or less essential to increasing participation rates are:

- reminder services for women who do not otherwise attend rescreening;
- fail-safe systems to ensure follow-up of women with significantly abnormal smears;
- compilation of individual womens' cervical screening histories;
- monitoring of screening rates and cervical cancer.

The CCESR notes that cervical cytology registries, which record the results of Pap smears, would fulfil all these functions. The report recommends the establishment of cervical cytology registries, together with funding for cancer registries, to monitor cervical cytology and cancer cases.

The Commonwealth notes that alternative arrangements may operate in some States. Registries may raise issues of privacy, although this was not found to be an issue by the two pilot projects which operated registries. The Commonwealth seeks States' and Territories' views on preferred methods for providing these functions.

There are also questions about inter-state mobility and reliability of addresses which will have to be examined if effective reminder systems are to be designed using registers.

COMMUNICATIONS PROGRAM, INCLUDING MEDIA

The communications program, or strategy, would include national and local elements. At the national level, a spokesperson will be appointed to assist in promoting the screening policy to professional and consumer groups. Professional advice on marketing the policy may also be sought.

States should examine their needs for educational and promotion campaigns as an integral element of the strategy.

SPECIAL PROGRAMS AND PROJECTS FOR HIGH RISK GROUPS

In accordance with the recommendations of the report, States would be expected to continue to be responsible for recruitment and recall services, including special services for high risk groups.

Attachment 2 seeks to draw together strategies to increase participation that were found to be effective in the evaluation. States/Territories should identify their plans in the light of regional requirements.

WORKFORCE EDUCATION AND TRAINING

The Report refers briefly to professional education about cervical cancer screening, and includes some estimates of increased cervical cytology workload generated by a national screening program.

The undergraduate and ongoing education needs of medical and nurse practitioners, both in relation to smear taking and screening practices, need to be examined in depth, together with training of cytotechnologists. The Commonwealth could initiate appropriate studies.

DATA COLLECTION AND MONITORING

Screening services are by their nature costly and are particularly dependent on routine collection and analysis of data to ensure they are efficient, effective and well targeted. They are an indispensable element in epidemiological and clinical research on this disease.

Monitoring should encompass:

- Participation rates of the target population and sub-populations;
- adequacy of the tests being taken;
- level of abnormality found on tests;
- accuracy of the test reports;
- long-term outcomes of treatment for screen-detected abnormalities;
- impact on cervical cancer morbidity and mortality; and
- the cost of the screening program.

TRANSITIONAL PLANS

The Commonwealth is concerned to ensure continuity of programs currently operating in States/Territories. State responses should include plans for continuation of projects or other arrangements for them to be superseded or replaced, as appropriate.

COSTS

The Commonwealth is seeking an indication of estimated extra costs for elements of an organised approach to cervical screening. This should include capital and operating costs, as applicable, for example;

- administration/co-ordination;
- cervical cytology registries;
- subsidy for cancer registries;
- communications program, including media;
- special programs and projects;
- workforce education and training;
- data collection and monitoring.

FUNDING

Under current funding arrangements for cervical cancer screening, the Commonwealth meets most of the expenditure by governments, estimated in the report at $125 million per annum. States meet some costs for screening support services and traeatment in public hospitals. Women attending screening services also contribute substantial amounts.

There is a wide range of funding mechanisms currently in use both for smear taking, cervical cytology and follow-up treatment and management of abnormalities. Funding for the other parts of the screening pathway is limited.

The report examines a number of possible funding mechanisms aimed at providing appropriate incentives to improve standards of service and reducing the apparent anomalies arising from multiple funding sources. The future source, extent and nature of the funding of the other elements of the screening pathway is a matter which requires attention.

Further investigation of possible funding issues is being undertaken in conjunction with program development.

EVALUATION

The Commonwealth would probably wish to follow normal practice and seek an independent evaluation of the program.

States and Territories would be consulted in developing terms of reference and methodologies for the evaluation. The evaluation would need to scrutinise all steps of the screening pathway and be able to rely largely on data collected routinely as part of the monitoring of the program.

It is important that arrangements for the evaluation be put in place early in the life of the new program, with a view to reporting after three years of operation, say 1994/95.

Commonwealth Department of Community Services and Health
January 1991

Cervical cancer screening in Australia – options for change

Volume 1

Final report

Prepared by the Cervical Cancer Screening Evaluation Steering Committee of the Australian Health Ministers' Advisory Council
31 August 1990

Victorian Cytology Service

Director: Gabriele Medley MB BS FRCPA FIAC
Deputy Director: Heather Mitchell MB BS FRACP MSc

31 August 1990

Dr W T McCoy
Chairman
Australian Health Ministers' Advisory Council
Department of Community Services and Health
GPO Box 9848
CANBERRA ACT 2601

Dear Dr McCoy,

It is with pleasure that I submit the report of the Cervical Cancer Screening Evaluation Steering Committee. The report draws heavily on information gained from the first 25 years of cervical cancer screening in Australia and on evaluation data which has been provided from the pilot projects. The report includes a number of recommendations for changes to the existing screening system which the Steering Committee believes to be both timely and appropriate within the Australian health care system.

On behalf of the Steering Committee, I commend the report to you.

Yours sincerely,

Heather Mitchell

Heather Mitchell
Chairperson

CONTENTS

1. EXECUTIVE SUMMARY AND RECOMMENDATIONS

1.1 EXECUTIVE SUMMARY

Background

This is a summary of the accompanying report on policy aspects of developing national strategies for extensive cervical cancer screening programs within Australia.

Over a period of more than two years, the Cervical Cancer Screening Evaluation Steering Committee has considered in depth the existing approach in Australia, the results from pilot projects and the options for change. The Committee took as its starting point local and international evidence about how cervical cancer screening can be efficiently and effectively delivered. This report is the result of those deliberations.

Requirements for effective cervical cancer screening

The role of the Pap smear in preventing invasive cervical cancer through the detection and subsequent treatment of potentially precancerous cervical abnormalities has been well established around the world. The greatest impact has been achieved in countries or regions which have had organised screening programs. Evidence from these programs suggests that up to 90% of cancers of squamous cell type can be prevented.

Both the World Health Organisation and the International Agency for Research on Cancer have made recommendations about the requirements for an effective cervical cancer screening program. An effective programme needs attention to all aspects of what is referred to as "the screening pathway": screening of the target population at regular intervals; provision of acceptable and accessible services for taking Pap smears; provision of high-quality services for reporting smears; ensuring follow-up of women with abnormal smears; and a system for the monitoring and evaluation of the whole screening program. In short, a comprehensive approach is needed.

Many of the elements identified by the World Health Organisation and the International Agency for Research on Cancer as being essential to an effective program are not addressed at all in the current approach to cervical cancer screening within Australia. After twenty-five years of experience, there is a considerable body of expertise in many of the clinical aspects of screening and in the management of women with abnormalities. However, it is estimated that only one-half of the cases of cervical cancer are being prevented.

Cervical cancer screening in Australia

With the increasing enthusiasm for disease prevention, cervical cancer screening has been a growth area in the health system, but much of the current effort is poorly directed and cost-inefficient.

Almost two million Pap smears will be taken during 1990. Claims for Pap smears are among the top five pathology items billed to the Health Insurance Commission. Claims for 100,000 colposcopies and 75,000 biopsies and diathermies from the private sector will be lodged with the Health Insurance Commission during 1990. These figures do not include colposcopies, biopsies and diathermies performed in the public sector. Current expenditure by Government on cervical cancer screening is in the order of $125 million per annum. The costs to women in attending the services provided is in the order of $37 million per annum, bringing the total outlay for the community to approximately $162 million per annum.

For this expenditure, 700-750 cases of cervical cancer are prevented. At least 700 additional cancers could be prevented each year. The majority of women who develop invasive cervical cancer are inadequately or never screened.

While the impact of this expenditure may be evident in declining rates of cervical cancer incidence and mortality during the next decade, it is acknowledged with concern that our not inconsiderable screening efforts during the 1980s appear to have reduced the burden of cervical cancer by only one-half of what could be achieved under an organised system.

Problems with the current approach

Specific problems which are apparent with the current approach to cervical cancer screening include the following:

Program design

1. The absence of a framework for cervical cancer screening to ensure that the achievement of goals and targets is optimal for the monies expended.

Coverage of the target population

1. The lack of agreement on an age group for screening.

2. The lack of agreement on the recommended rescreening interval.

3. The absence of a budget and responsible body to ensure high coverage of the target population resulting in significant under-screening of some subgroups of the population.

4. No access to a population list for personal invitations.

Services

1. The lack of a choice of service providers in some areas of Australia.
2. A declining public sector for laboratory reporting of Pap smears and training of cytotechnologists and cytopathologists.
3. The absence of a fail-safe system for ensuring that women with significant abnormalities are followed-up.
4. Lack of agreement on appropriate management for women with minor screen-detected abnormalities.

Monitoring/quality control

1. Lack of data to enable an accurate assessment of regional, State/Territory and national screening rates among eligible women.
2. No comprehensive data on the accuracy of the tests.
3. The lack of a system for monitoring the outcome of treated women.
4. The lack of evaluation and monitoring of cervical cancer screening activities and of progress in achieving goals and targets.

These problems have been evident in all countries and regions which have relied on an unstructured approach to screening. They are reflected in a relatively small impact on the morbidity and mortality from cervical cancer for the monies expended.

Pilot projects

Funding to evaluate new initiatives in the problem areas in cervical cancer screening was provided to all States and Territories from the "New Initiatives for Women" budget which paralleled the establishment of the Committee. Since 1987, approximately $2.5 million has been spent on the pilot projects and $0.5 million on central evaluation.

Reports from each pilot project are included in the supplementary volume. Data from the pilot projects have been extensively used in preparing this report. Given the paucity of evaluation work in the area of cervical cancer screening, these data have been critically important.

The lack of any comprehensive monitoring system was a serious limitation on the capacity of most pilot projects to be maximally effective in evaluating problem areas. For example, pilot projects in five States/Territories trialed new strategies to increase the participation of women in cervical cancer screening. All were hindered by the lack of a database which could establish whether the women who were screened in response to these recruitment strategies were previously under-screened, never screened or well screened. As confirmed by two pilot projects, the self-reported screening history by women is subject to serious inaccuracies.

The effectiveness of the current system

The problems previously identified in this summary give rise to a poor cost-effectiveness. Almost $45,000 is spent for each life year saved under the current system. This is not cost-effective in comparison with many other areas of health spending. The cost-effectiveness could be substantially improved by the introduction of an organised approach.

Particular areas of concern with respect to the low effectiveness and the low cost-effectiveness are:

1. The interval at which women are screened.

   There is no accepted interval for rescreening. The interval recommended by professional bodies varies from one to three years. A pilot project survey in South Australia showed that more than one half of the women thought the appropriate interval between smears was 6-12 months. This lack of a uniform policy translates into frequent and expensive rescreening of a low risk population. Furthermore, many clinicians suggest or undertake frequent rescreening because of the lack of a reminder system for women who are due for tests or because of concerns over the quality of the smears taken and the accuracy of the reporting.

2. The age group which is screened.

   Most tests are taken from young women who are at low risk of cervical cancer. Screening the 18-24 year age group, for example, may result at best in an additional 33 cancers per year being diagnosed, but at a cost of $16.5 million per death averted. Older women who are at highest risk of cervical cancer are poorly screened under the current system. The inclusion of the 65-69 year age group in a screening program, for example, may result in 126 additional cancers being detected per year and would improve the cost-effectiveness of a national screening program.

3. Laboratory costs.

   There is substantial variation in the level of funding provided to public and private sector laboratories. Public sector laboratories, which receive less funding than private sector laboratories, account for a declining number and proportion of the Pap smears which are reported. In addition to the adverse effects of this trend on costs to governments, this decline has very serious implications in that almost all training of cytotechnologists and cytopathologists is undertaken in the public laboratories. Furthermore, for reasons of equity, it is essential that there is access to laboratories which do not charge a patient moiety.

4. The high proportion of screened women who receive further investigations.

   Almost 50% of current expenditure on cervical cancer screening is accounted for by investigation of women who receive abnormal Pap smear reports. While any cervical cancer screening program involves the treatment of a group of women with abnormalities which are considered to have a precancerous potential, the proportion of women who are currently investigated far exceeds the proportion who would develop cervical cancer if no treatment were given.

There can be no improvement in the cost-effectiveness without change. In addition to the recommendations listed below, this report discusses a range of initiatives which could be used to improve the cost-effectiveness, with a summary of the advantages and disadvantages of each. Not all of these initiatives are accorded the status of recommendations by this Committee.

Options for change

In broad terms, there are three choices for government with respect to the organisation and delivery of cervical cancer screening in Australia:

1. Implement a new system of screening

   A range of alternative screening systems can be contemplated. The Committee believes a totally new system of cervical cancer screening would be strongly opposed by women and clinicians, and is unnecessary.

2. No change: continue with the current arrangements

   The current arrangements are inefficient in reducing the burden of cervical cancer and are excessively expensive. The ongoing morbidity and mortality from cervical cancer are clearly a concern given the evidence of better outcomes achieved in other countries.

3. Augment existing screening with an organised approach

   This is the preferred option. The recommendations listed below detail the preferred strategy for change to the current system to provide for an organised approach which should allow an efficient and effective screening program to be delivered.

The Committee unanimously agreed to the recommendations. The Committee believes they will have the broad support of both health professionals and women. However, the Committee recognises that there are many persons and organisations within Australia who hold strong views on how cervical cancer screening should be delivered. Many are unaware of the breadth of problems with the current approach. These persons and organisations will need to be convinced both of the need for change and of the correctness of the new approach. The magnitude of this task should not be underestimated.

Organised screening does not mean the establishment of an alternative system for the taking and reporting of Pap smears. The present arrangements should continue, with most Pap smears being taken by general practitioners and a public-private mix of laboratory services for the reporting of Pap smears. However to be successful, organised screening will need to address each element of the screening pathway and will involve the funding of two additional areas of the screening pathway:

(i) a formal recruitment plan for call and recall of women

(ii) a monitoring system to evaluate the uptake, adequacy, accuracy, abnormality rates and cost of screening.

The establishment of cervical cytology registries in each State/Territory would facilitate the achievement of both of these needs.

These two new initiatives would address at source two of the most basic and far reaching areas of difficulty with the current approach. Unless these two difficulties are satisfactorily addressed, it is highly unlikely that the medical community will accept anything but a policy of annual screening.

Cost

The cost to government of the organised approach recommended in this report is less than the current expenditure by government. No additional expenditure by government should be necessary until 1994, by which time the growth anticipated in screening participation rates will have offset the cost savings anticipated from introducing the organised approach. The funding of the two new areas of recruitment and monitoring should be achieved by a reallocation of the savings made from women accepting routine screening no more frequently than every two years. It is anticipated that the uniform adoption of a two year rescreening interval would save $60 million over the 1991-1993 period.

If the age for commencement of screening was raised, then savings would continue well beyond 1994.

1.2 RECOMMENDATIONS

1. The introduction of an organised approach to cervical cancer screening is essential if Australia is to achieve a maximal impact on cervical cancer morbidity and mortality from the resources available. The organised approach should apply to all aspects of cervical cancer screening, including recruitment and recall, smear taking and reporting, follow-up and management of women with abnormalities and monitoring. Delivery of screening is most appropriately undertaken at the level of States and Territories. National policy development is essential. National monitoring of screening and of progress in controlling cervical cancer is required.

2. To improve screening coverage, funds should be made available for:

   - appropriately targeted recruitment of women for screening. Priority should be given to under-screened groups of women, including older women, women of low socioeconomic status, women of non-English speaking background and Aboriginal women. Initiatives for increasing recruitment should be directed towards both women and health professionals;

   - a range of services for taking Pap smears where needed to reach under-screened groups of women. Such services should seek to ensure that women have access to a female practitioner;

   - a reminder system for all women who are overdue for their next test. This system should be complementary to and act as a back-up for reminder systems which may be operated by service providers.

   This funding should be cost shared by the Commonwealth and the States/Territories.

3. Cervical cytology registries should be established by States and Territories to provide an infrastructure for an organised approach to screening. The registries should:

   - remind women to attend for screening;

   - provide a fail-safe system to ensure follow-up of women with significantly abnormal Pap smears;

   - provide individual women's cervical screening histories to laboratories and clinicians to aid reporting and management;

   - monitor the effects of initiatives to improve participation by women in screening;

- monitor the screening histories of women who develop cervical cancer.

4. For the present, women should be screened from the age of 18 years or within a year of first sexual intercourse, whichever is later. Screening should cease at 70 years of age. In view of cost-effectiveness considerations, a consultative process and a review of relevant data on the age to commence screening should be undertaken.

5. Women should initially have two annual Pap smears and then be screened every two years if the initial two Pap smears are normal. This two year interval is recommended, conditional upon the operation of comprehensive reminder systems and of systems to monitor the accuracy of screening tests. This screening policy should be uniformly promoted in cervical cancer screening education and recruitment campaigns across Australia.

6. Invitations using population based registers are potentially an important and efficient method of increasing screening coverage. Community discussion of the acceptability of the use of population registers (such as the electoral register) for public health projects of this type should be initiated, and the legal issues and legislative requirements should be closely examined by governments as a matter of urgency.

7. Ongoing monitoring at a population level of all phases of the screening program should be routine. Specific funding should be provided for this monitoring. The monitoring should encompass:

   - participation rates of the target population and sub-populations;
   - adequacy of the tests being taken;
   - level of abnormality found on tests;
   - accuracy of the test reports;
   - long-term outcome of treatment for screen-detected abnormalities;
   - impact on cervical cancer morbidity and mortality;
   - the cost of the screening program.

   The establishment of registers of women having tests would greatly facilitate this monitoring.

   Funding for monitoring should be cost shared by the Commonwealth and the States/Territories.

8. To assist in monitoring the impact of the screening program, cancer registries should be funded to maintain up to date records of incidence and mortality as well as recording the stage (microinvasive or more advanced as indicated by pathology reports) and histologic type for each case of cervical cancer.

9. Practitioners should receive continuing education about cervical cancer screening. Laboratories should provide regular feedback to practitioners on the quality of their Pap smears. Opportunities should be available in each State/Territory for practitioners to improve their skills in encouraging women to be screened, in taking Pap smears and in counselling women with abnormalities.

10. Laboratories should be accredited for the purposes of public funding for cervical cancer screening on the basis of their satisfactory participation in specified quality assurance activities which assess the accuracy of their day to day reporting and on their willingness to contribute information to appropriate monitoring bodies.

11. To ensure the continued viability of high quality public sector laboratories with facilities for training cytotechnologists and cytopathologists, a funding level should be provided to such laboratories to enable them to provide a comprehensive, timely and efficient service to practitioners.

12. In conjunction with appropriate professional bodies, a review of all available evidence to develop recommended standardised management of women with minor screen-detected abnormalities should be funded as a matter of urgency.

13. Under the auspices of an appropriate national body, a National Cervical Cancer Screening Advisory Committee should be established. The Committee should be supported by a secretariat. The Committee should have the following roles:

    - developing and reviewing cervical cancer screening policies and making recommendations to promote their acceptance;

    - examining and providing information relevant to the development of funding mechanisms for cervical cancer screening;

    - making recommendations to bodies such as the National Pathology Accreditation Advisory Council, National Association of Testing Authorities and the Royal College of Pathologists of Australasia on the minimum accuracy standards which are appropriate for laboratory accreditation;

- reviewing cervical screening activities across Australia and making recommendations on areas requiring further action;

- commissioning the preparation of reports on relevant issues.

The secretariat should be headed by a senior health professional in the Commonwealth Department of Community Services and Health with full-time responsibility for coordinating the area of cervical cancer screening. In addition to supporting the Committee, this person should have the following roles:

- preparing reports for the National Committee which highlight advances and deficiencies;

- liaising with bodies associated with cervical cancer screening, particularly with respect to national policy and national coordination;

- acting as a clearing house, disseminating information on promotional and educational resources and technical information between the various bodies involved in screening;

- where appropriate, assisting States/Territories in the development of State/Territory plans and in the development of mechanisms for reviewing the performance of screening activities.

This person should be supported by appropriate administrative and technical staff as needed.

Funding should be ensured for collating and interpreting national monitoring statistics of relevance to cervical cancer screening.

14. A major review of the cervical cancer screening program should be undertaken in 1996/1997 or after three years of steady-state operation of the new approach. This review should consider the need for an ongoing committee and secretariat.

2. TERMS OF REFERENCE

The Committee was given the following terms of reference by the Australian Health Ministers' Advisory Council:

1. To ensure the adequate conduct of and give direction to the Screening Evaluation Coordination Unit of the Australian Institute of Health.
2. To advise the Australian Health Ministers' Advisory Council on the various policy aspects of developing national strategies for extensive screening programs.

3. MEMBERSHIP OF THE STEERING COMMITTEE

The Steering Committee comprised the following members, who served from July 1988 to August 1990 except where indicated:

Dr Heather Mitchell (Chair)
Deputy Director
Victorian Cytology Service
Melbourne

Ms Carla Cranny
Director
Health Service Delivery
Western Sydney Area Health Service
New South Wales Department of Health
Sydney

Dr John Donovan — From February 1989
Principal Medical Adviser
Australian Institute of Health
Canberra

Dr Anne Fisher
General Practitioner
Sydney

Dr Keith Free
Coordinator,
Gynaecologic Oncology
Royal Brisbane Hospital
Brisbane

Dr Julienne Grace — From February 1990
Cytopathologist
Royal Prince Alfred Hospital
Sydney

Dr Jenny Grounds
Community Health Practitioner
Melbourne

Mr Roy Harvey — Until February 1989
Head
Health Status Division
Australian Institute of Health
Canberra

Dr Paul McCann
Medical Superintendent
Royal Hobart Hospital
Hobart

Dr Cathy Mead
Medical Services Adviser
Department of Community Services and Health
Canberra

Ms Diane Moore
Manager
Women's Cancer Prevention Unit
Health Department of Western Australia
Perth

Dr Frank Pacey Cytopathologist Institute of Clinical Pathology and Medical Research Westmead Hospital Sydney	Until February 1990

Dr David Roder
Director of Epidemiology
South Australian Health Commission
Adelaide

Dr Michael Fett (Secretary/Convenor)
Head
Screening Evaluation Coordination Unit
Australian Institute of Health
Canberra

Co-opted member

Dr Judy Straton Lecturer Division of Public Health Department of Medicine University of Western Australia Perth	From February 1989

4. BACKGROUND

This report is an outcome of the National Cervical Cancer Screening Evaluation undertaken during 1988-1990. The evaluation was established as a joint initiative of Commonwealth, State and Territory health authorities under the auspices of the Australian Health Ministers' Advisory Council. It followed the November 1987 recommendations of the Australian Health Ministers' Advisory Council Sub-committee on Breast and Cervical Cancer Screening.

At that time there was concern about under-screening among substantial sections of the female Australian population along with over-screening of other groups, the variable quality of Pap smear taking and reporting, the lack of a method for ensuring that women with abnormal Pap smears received appropriate follow-up and the cost of Pap smear reporting.

In 1986, guidelines outlining the essential elements of cervical cancer screening programs were published by the World Health Organisation and the International Agency for Research on Cancer (Hakama et al, 1986). A review of the current Australian situation in relation to these guidelines is outlined in Table 4.1. This shows that, after 25 years of cervical cancer screening without an organised approach, there are major areas of deficiency in the delivery of cervical cancer screening. These deficiencies preclude the cost effective delivery of extensive screening in Australia.

TABLE 4.1 Essential elements of an organised approach to cervical cancer screening and the current Australian situation

Essential elements(a)	Australian situation
The target population has been identified	No agreement on age group or screening interval
Individual women are identifiable	No access to population list
Measures are available to guarantee high coverage and attendance, such as a personal letter of invitation	No funding No responsible body

TABLE 4.1 Continued

Essential elements	Australian situation
There are adequate field facilities for taking the Pap smears and adequate laboratory facilities to examine them	Sufficient number of laboratories and medical practitioners to take Pap smears. Limited range of Pap smear taking services acceptable to all women in some areas
There is an organised program for quality control of the taking and interpreting Pap smears	Limited in scope. Variable in application
Adequate facilities exist for diagnosis and for appropriate treatment of confirmed neoplastic lesions and for the follow-up of treated women	Adequate facilities for diagnosis and treatment but no formal system for monitoring the status of treated women
There is a carefully designed and agreed referral system, an agreed link between the women, the laboratory and the clinical facility for diagnosis of an abnormal screening test, for management of any abnormality found and for providing information about normal screening tests	No fail-safe system for women with abnormal Pap smears. Otherwise satisfactory
Evaluation and monitoring of the total program is organised in terms of incidence and mortality rates among those attending, and among those not attending, at the level of the total target population. Quality control of these epidemiological data should be established.	None

(a) Source: Hakama et al, 1986 p.289

Australian initiatives since 1987

To address these problems, in 1987 the Commonwealth committed $2.5M to the "New Initiatives for Women" budget for the national evaluation of innovative pilot projects designed to test a range of methods for providing high quality services which were acceptable and accessible to women, and which represented value for money. Cost shared funding with the States and Territories was provided for service delivery by projects; full funding was provided for evaluation of the projects.

In early 1988, the Australian Health Ministers' Advisory Council created the Cervical Cancer Screening Evaluation Steering Committee to oversee the evaluation and to make recommendations on national approaches to cervical cancer screening. To coordinate the evaluation and to assist the Committee in preparing its report, a Screening Evaluation Coordination Unit was established at the Australian Institute of Health. Of the $2.5M, $500,000 was used to contribute to the cost of the Unit.

This report draws heavily on data collected by the pilot projects, together with other relevant information obtained from overseas projects and current screening activities within Australia. With cervical cancer screening having been available for over 25 years and with numerous reports being published from other countries, it was considered unnecessary to explore all possible options again. Rather, this report takes as its starting point strategies which have been found effective in Australia and in other countries, or which have been recommended by the International Agency for Research on Cancer.

The pilot projects

The pilot projects specifically focused on elements of the cervical cancer screening process which have proven most problematic in Australia.

Methods of improving attendance of women at screening were examined in The Hunter Valley of New South Wales, in Queensland urban, rural and remote areas, in outback areas of Western Australia, in the Upper Spencer Gulf region of South Australia, in the Australian Capital Territory and among traditional Aboriginal women in the Northern Territory. Methods examined include local and mass media campaigns, community networks, general practitioner recruitment and letters of invitation to women.

Innovative services for taking Pap smears were tested in New South Wales, Queensland, Western Australia, South Australia, the Northern Territory and the Australian Capital Territory. These services comprised trained nurses taking Pap smears in a variety of locations including special Pap smear clinics, women's health clinics and locum female doctors working in general practice surgeries.

Issues relating to the quality of the taking and reporting of Pap smears were examined in two national surveys of laboratories.

The adequacy of referral mechanisms to ensure that women with abnormal Pap smears are offered treatment was examined as part of the Upper Spencer Gulf project. A related study is in progress in Victoria.

In Victoria and Western Australia, cervical cytology registries have been established to examine their feasibility and their potential contribution to an organised approach to cervical cancer screening.

A survey of the accuracy of self-reported frequency of Pap smears was undertaken in NSW.

Finally, consultancies were contracted to examine funding mechanisms and workforce requirements.

Table 4.2 summarises the areas covered by the pilot projects. Where they illustrate issues or solutions to problems in cervical cancer screening, data from these projects are incorporated in the main body of the report. Short reports from each project are presented in Volume 2.

TABLE 4.2 Areas covered by pilot projects

Area	Pilot project
Maximising coverage of cervical cancer screening	Rural New South Wales Urban, rural and remote communities in Queensland Eastern goldfields region of Western Australia Upper Spencer Gulf region of South Australia Australian Capital Territory
Pap smear taking services	New South Wales Rural Queensland Eastern goldfields region of Western Australia Upper Spencer Gulf region of South Australia Australian Capital Territory Outback areas of the Northern Territory
Rescreening interval	Consensus conference
Accuracy of self-reporting	New South Wales
Laboratory services	National studies undertaken by the Screening Evaluation Coordination Unit, Australian Institute of Health

TABLE 4.2 continued

Referral mechanisms	Upper Spencer Gulf region of South Australia Urban Victoria
Cytology registries	Victoria Western Australia

Structure of this report

The substance of the report is contained in the following four chapters:

Chapter 5 Cervical cancer and screening in Australia

This chapter presents information on the effectiveness and organisation of cervical cancer screening, patterns of cervical cancer and cervical cancer screening in Australia, related expenditure and the current shortcomings in cervical cancer screening.

Chapter 6 Components of an organised cervical cancer screening program

This chapter discusses the requirements of an organised approach to cervical cancer screening, presents relevant pilot project data and identifies solutions to current deficiencies. It covers all components of the screening process, from recruitment of women to screening, Pap smear taking, laboratory reporting and follow-up of women with abnormal Pap smears, as well as education and monitoring.

Chapter 7 The economics of cervical cancer screening

This chapter presents estimates of the cost and cost-effectiveness of cervical cancer screening, including recruitment, Pap smear taking and reporting, notification of results, follow-up of women with abnormal Pap smears, quality assurance and monitoring and evaluation. The chapter also discusses the options for the cost-effectiveness of cervical cancer screening.

Chapter 8 Implementing an organised approach to cervical cancer screening in Australia

This chapter emphasises the importance of introducing an organised approach to cervical cancer screening and examines the best way of undertaking this in the Australian context, where responsibility for health is divided between the Commonwealth and the States and Territories.

Accompanying the report is a supplementary volume, Volume 2, which comprises brief reports from the pilot projects and consultancies. These reports are the work of the individual project teams and should provide much useful information for those planning or operating screening services, as well as for researchers.

5. CERVICAL CANCER AND SCREENING IN AUSTRALIA

5.1 CERVICAL CANCER IN AUSTRALIA

5.1.1 Pathology of cervical cancer

There are two principal forms of cervical cancer: squamous cell carcinoma and adenocarcinoma. Approximately 80%-85% of invasive cervical cancers are squamous cell carcinomas, 12%-15% are adenocarcinomas and 3%-5% are adenosquamous carcinomas and other rarer forms.

Squamous cell carcinoma of the cervix is preceded, mostly over a period of years, by a spectrum of asymptomatic abnormalities known as cervical intraepithelial neoplasia (CIN), graded as CIN I, II and III where CIN III is the most serious. CIN can be detected on a Pap smear. Some women with CIN will develop cervical cancer if the CIN remains untreated. While the precise proportion is unknown, 20% of the women who retained a cervix and who had persistent CIN III at the National Women's Hospital, Auckland developed invasive cervical cancer over 20 years (McIndoe et al, 1984). It is not possible to identify which cases of CIN will progress or regress. Therefore all cases need to be treated. Treatment of CIN can prevent progression to invasive cervical cancer, thus avoiding the need for hysterectomy and other radical treatments.

Women with invasive cervical cancer mostly present because of abnormal bleeding, a vaginal discharge or symptoms related to spread of the cancer. Treatment at this stage usually involves hysterectomy, radiotherapy and/or chemotherapy or a combination of these treatments. One third of the women diagnosed with invasive cervical cancer will have died of the disease by five years after diagnosis (Bonett and Roder, 1988). The morbidity experienced by women with incurable disease is prolonged and unpleasant. It commonly involves pain from spread of the cancer, kidney failure, incontinence and extreme wasting. This morbidity is largely preventable by effective screening.

5.1.2 Patterns of cervical cancer and precancer in Australia

Incidence

Cancer of the cervix remains a significant cause of morbidity and mortality in Australia. Despite being substantially preventable, it is the sixth most common cancer of women. In addition, in comparison with some other cancers, it affects a younger group of women, so that its personal and social impact is relatively high.

In the absence of screening, it has been estimated that the risk of developing squamous cell carcinoma of the cervix in a Western style country would be one in 64 for the age range 20-64 years. (Hakama et al, 1986, p.201).

In 1985 there were an estimated 1037 new cases of cervical cancer within Australia. Figure 5.1 shows the age distribution of these cases. It can be seen that cervical cancer is relatively rare in women under 30 years. While the highest incidence rates are in the 60-69 year age group, the greatest number of cases occur in the 30-39 year age group as there are more women in this age group.

Trends in the incidence of cervical cancer

National incidence data for cervical cancer are only available for 1982 to 1985 (presented in Appendix 4, Table 2). Over this short period, there has been a 2.8% increase in the age standardised incidence rate. Some of this increase could be due to the detection of microinvasive cancer in screened women; some could be due to prevalent cancers being detected as unscreened women are screened for the first time. Without knowledge of the stage and histologic type of cancer, it is difficult to make definitive comments about trends.

Data on incidence over moderately long periods of time are available from the New South Wales and South Australian Cancer Registries. In New South Wales, over the ten year period from 1973 to 1982 the incidence of cervical cancer decreased on average 1.3% per year, after adjusting for the estimated fraction of women who had undergone hysterectomy (McCredie et al, 1989). This reduction in incidence was observed in all age groups above 35 years. In the age group 15-34 years there was no change in incidence between 1973 and 1982.

In contrast, in South Australia between 1977 and 1986, an increase in the recorded incidence of cervical cancer of approximately 80% was observed among women under 50 years of age. There was a decrease of approximately 25% in older women (Bonett et al, 1989).

Data collected at the level of individual State/Territory are subject to fluctuations associated with small numbers. To better monitor the impact of cervical cancer screening in Australia, there is a need for up-to-date national statistics, including stage and histologic type of cancer. Details of stage required include knowledge of whether the case was of microinvasive cancer (the detection of which can be considered a success of a screening program) or invasive cancer.

Mortality

Mortality from cancer of the cervix increases with increasing age (Giles et al, 1987). There were 350 deaths in 1988 from this essentially preventable cancer. A majority (77%) of deaths occurred in women aged more than 50 years. Fifteen deaths occurred in women aged less than 35 years, representing 4.3% of all deaths from cancer of the cervix.

The increased mortality amongst older women is in part due to the later stage at which cancer is diagnosed in older women compared with younger women (Bonett et al, 1989).

Trends in mortality from cervical cancer

From data published by the Australian Bureau of Statistics, a one third reduction in the death rate from cervical cancer has been observed since 1950. Cervical cancer screening was introduced to Australia in the 1960s. Participation through the 1970s and early 1980s was probably quite low (approximately one quarter to one third of women in some age groups may have been screened regularly). No definite impact on the decline in mortality rates can be attributed to cervical cancer screening.

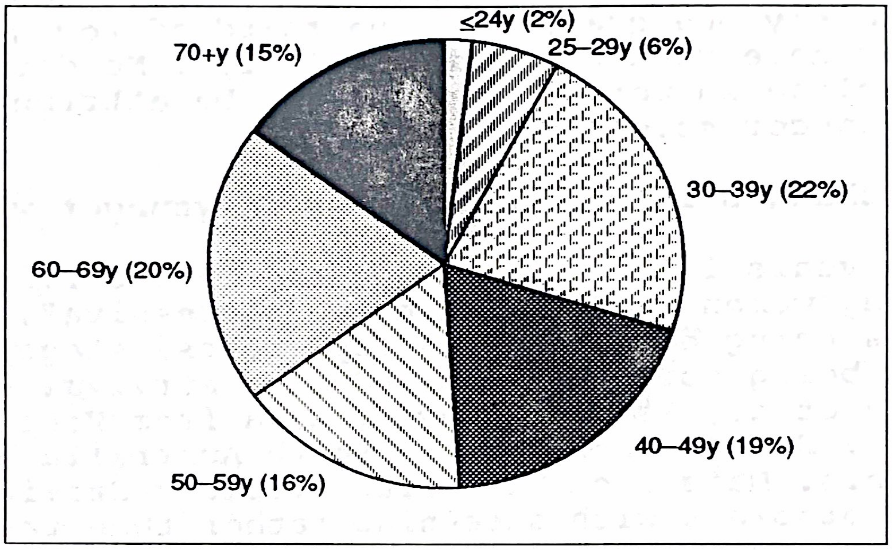
Possible changes in cervical cancer in younger women

In recent years it has been suggested that cervical cancer among young women is becoming more "aggressive", with no precursors being observable on Pap smears, stage at diagnosis being more advanced and case survival being worse (Coppleson et al, 1987). However, data from Victoria, Queensland, New South Wales and South Australia do not support this. Data from Victorian Cytology Service suggest technical problems with screening rather than rapid onset cancer is the cause of most negative reports in close proximity to a diagnosis of cervical cancer (Mitchell et al, 1990). In Queensland there has been a shift to earlier stage at diagnosis of cervical cancer and improvement in case survival rates when data for 1982-1988 are compared with 1960-1964 (Free et al, submitted for publication). In New South Wales during the period 1973-1982 there was no evidence of a trend towards more severe disease in young women (McCredie et al, 1989) and in South Australia, case survival was unchanged for young cases diagnosed in 1977-1981 and 1982-1987 (Bonett et al, 1989).

However, recent fluctuations have been evident in the mortality rates for younger women (Holman and Armstrong, 1987). Profiling age cohort effects to 1988 reveals that, since 1975-79 when an impact from cervical cancer screening may have become evident, the mortality has been declining among women aged 45 years or more and stable among women aged 35-44 years. An increase in mortality has been documented among women aged 30-34 years; the average number of deaths per year in this age group since 1985 has been 14.8 compared with 9.8 per annum in 1975-1979 and 12.6 per annum in 1980-1984.

In view of the clinical concerns, it is important that this issue be kept under close examination. This can only be done if adequate national monitoring data are available.

Figure 5.1: Age distribution of new cases of cancer of the cervix, Australia 1985 (total of 1,037 cases)



Source: State and Territory Cancer Registries. 1985 New South Wales incidence projected from 1982–84 data. Northern Territory incidence for each age group/calender year estimated by modelling from total number of cases in each year and number of cases in each age group for 1982–1985 combined. Australian Capital Territory incidence estimated from estimated New South Wales incidence and estimated Australian Capital Territory population.

Prevalence and trends in CIN

Data on CIN are not routinely collected by cancer registries, thus only limited data are available. Data from the Victorian Cytology Service between 1970 and 1988 indicate that the prevalence of CIN has gradually increased from 4.6 per 1000 women screened to 17.7 per 1000 women screened. This increase is largely due to an increase in the prevalence of equivocal CIN, CIN I and CIN II. There has also been a progressive lowering of the age at which CIN is most common, from 40-49 years in 1970-1973 to 25-29 years in 1982-1988. It is possible that younger women have always had high CIN rates. As they were unscreened in the early years, their CIN rates are unknown for that period (Mitchell and Medley, 1990).

5.1.3 Risk factors for cancer of the cervix

The risk of cervical cancer has been found to vary in relation to a number of factors including age, country of birth, socioeconomic status, smoking, sexual history and infection with Human Papilloma Virus. It is not clear which of these factors are causal and which are only associations.

Cervical cancer has long been known to be associated with low socioeconomic status. In Victoria, there is 33% higher incidence and 60% higher mortality in the lowest decile of socioeconomic status compared with the highest decile (Giles G, personal communication). This relationship is probably indirect and is likely to be partly due to correlations between socioeconomic status and Pap smear screening frequency.

The rates of cervical cancer in migrants to Australia vary according to the countries of origin (Table 5.1). The variations broadly reflect the rates in the countries of origin. The reasons for these variations are unknown, but are likely to be at least partly due to variations in socioeconomic status and other cervical cancer risk factors as well as to variations in screening history.

TABLE 5.1 **Age standardised incidence ratio of cancer of the cervix in New South Wales residents among female migrants to Australia by country of birth, averaged over the period 1972-84**

Country of birth	Standardised incidence ratio	95% confidence interval
Australia	100 (fixed)	
Asia	145	107-192
Eastern Europe	143	111-182
Northern Europe	134	105-167
New Zealand	129 *	89-179
England	98 *	84-114
Southern Europe	86 *	72-103
Middle East	64	41-95

Source: McCredie and Coates (1989)

* Not statistically significantly different from 100

A particularly important risk factor is being an Aboriginal Australian. The rate of diagnosis of cervical cancer for Aboriginal women in the Northern Territory in 1981-1985 was more than five times the rate in all Australian women (Honiari and Saint-Yves, 1987). In the Northern Territory in 1979-1983, the death rate from cervical cancer among all Aboriginal women was more than six times the rate among Australian women (Guest et al, in press). Lower screening rates among Aboriginal women probably contribute significantly to this higher incidence and mortality.

Given our incomplete knowledge of the exact causal mechanisms of cervical cancer, the prospects for preventing cervical cancer predominantly lie with screening. The known risk factors are widely distributed in the Australian community. Apart from the fact that women who have never had sexual intercourse are at very low risk, the known risk factors are sufficiently accurate in predicting cancer to define a high risk group that requires screening and a low risk group that does not. Thus cervical cancer screening must be carried out on a population basis to be effective.

5.2 CERVICAL CANCER SCREENING

5.2.1 Evidence for the effectiveness of cervical cancer screening

The optimal method for evaluating the effectiveness of screening in reducing mortality is via randomised controlled trials which minimise multiple sources of bias.

No randomised controlled trials of the impact of cervical cancer screening were undertaken prior to its introduction in the 1950s and 1960s. However, three decades of screening has provided substantial indirect evidence of its effectiveness in reducing the morbidity and mortality from cervical cancer.

Since the introduction of screening, studies have shown that the rate of new cases of cervical cancer has fallen 30-78% in those countries which adopted organised cervical cancer screening (Anderson et al, 1988; Hakama, 1982; Miller, 1986; Pettersson et al, 1985; Sijurdsson et al, 1989). Similarly, reports from the World Health Organisation for 1960 to 1980 show reductions of 20-70% in cervical cancer mortality in those countries which adopted cervical cancer screening (Cuzick and Boyle, 1988; Laara et al, 1987). However, these studies lack an unscreened comparison group, so it is not possible to know what would have happened if screening had not been introduced.

More useful information is provided by comparisons between areas with different levels of screening within a relatively homogeneous population. Such studies show that the mortality and incidence of invasive cervical cancer was lower in those areas which had a higher intensity of screening, usually measured as Pap smears per 1,000 women over a given period (Cramer, 1974; Lynge et al, 1989; MacGregor and Tepper, 1978; Magnus, 1987; Miller et al, 1976; Murphy et al, 1987). A Danish study demonstrated that not only was cervical cancer incidence and mortality influenced by the number of Pap smears taken, but that the proportion of eligible women screened was an important determinant of the impact of screening (Lynge et al, 1989).

Data from seven international studies have been used by the International Agency for Research on Cancer to estimate the reductions in cervical cancer incidence which would result if various screening policies were introduced (see Table 5.2). A more detailed table is presented in Appendix 4.

Comparable estimates have been obtained from other studies. For example, a study from Kaiser-Permanente in California (Morell et al, 1982) estimated that the percentage of cancer prevented for a one year, two year and three year interval respectively was 98.8%, 96.5% and 89.4%.

TABLE 5.2 Percentage reduction in cumulative incidence of invasive cervical cancer in women aged 35-64 years with different frequencies of screening

Interval between screening (years)	% reduction in cumulative incidence of cervical cancer	No. of tests in lifetime per women
1	93.5	30
2	92.5	15
3	90.8	10
5	83.6	6
10	64.1	3

Source: Hakama et al, 1986 p.141

5.2.2 Organised versus opportunistic cervical cancer screening

Cervical cancer screening can be provided by an organised approach or opportunistically. The latter comprises screening which is carried out when women present for consultations for other health matters and screening which is undertaken "on demand", where the woman requests it but outside a planned system of invitation (Hussain, 1990).

Organised screening encompasses:

- systematic and coordinated methods of ensuring regular participation by women to attend for screening and of notifying them of their results;
- outcome measures which monitor the technical quality of screening;
- mechanisms to ensure women receive appropriate assessment, counselling and treatment when necessary; and
- ongoing evaluation, monitoring and adjustment of screening and related services.

Data are available which compare the efficacy of organised and opportunistic screening: greater reductions in incidence and mortality of cervical cancer have been found in the two regions in Scotland with organised screening programs than in the remainder of Scotland, with no organised screening programs (Macgregor and Teper, 1978). Similarly, in Denmark the introduction of organised screening in some counties resulted in cervical cancer mortality in those counties dropping by 32%, even though there was little change in the number of Pap smears taken (Lynge et al, 1989).

A recent cost-effectiveness analysis of cervical cancer screening (Koopmanschap et al, 1990) concluded: "almost all examples of successful screening policies (successful with respect to participation and health effects) use invitation systems based on population registries (Berget, 1979; Hakulinen and Hakama, 1985; Johannesson et al, 1982; Magnus et al, 1987). The absence of a registry or of invitations appears to be closely correlated with low coverage (Olesen, 1986; Parkin et al, 1982). One exception is the British Columbia project (Anderson et al, 1988)".

The lesser effectiveness of opportunistic screening can be attributed to deficiencies at all stages along the screening pathway from recruitment to treatment. The deficiencies arise from a lack of clear objectives inherent in opportunistic screening, a lack of coordination within and between the components of the screening pathway and lack of coordinated quality control and monitoring. In contrast, systematic and organised screening explicity addresses and minimises these deficiencies. It also provides a framework in which national screening guidelines can be applied, activities such as training and accreditation can be coordinated, and problems with screening can be identified and addressed.

The unstructured approach used in Australia to date has resulted in lower screening rates among socially disadvantaged groups (e.g. women of lower socioeconomic status, women of non-English speaking background and Aboriginal women) and in older women (Armstrong et al, 1986). Reliance on the current system is likely to result in the perpetuation of substantial inequalities in access and participation, with women of high socioeconomic status continuing to be at a substantial advantage in relation to cervical cancer screening. The socioeconomic gradient in morbidity and mortality (section 5.1.3) provides compelling evidence of the consequences of an unorganised approach.

5.2.3 Patterns of cervical cancer screening in Australia

Rates of Pap smears in Australia

In the three year period 1987-1989, of Victorian women aged 20-69 years who had not had a hysterectomy, 64% appear to have been screened at least once (H. Mitchell, personal communication). For New South Wales, Western Australia, Northern Territory, Tasmania and the Australian Capital Territory combined, of women aged 20-69 years who had not had a hysterectomy, 62% had been screened at least once in the three year period 1987-1989 and 50% had been screened at least once in the two year period 1988-1989 (Table 5.4, Health Insurance Commission data, adjusted for estimated fraction of women with an intact uterus).

TABLE 5.3 Percentage of women screened at least once in the two year period 1988-1989 and in the three year period 1987-1989.

Age (years)	1987-1989 (3 year interval) (%)	1988-1989 (2 year interval) (%)
20-29	69	55
30-39	74	60
40-49	67	55
50-59	49	40
60-69	25	20
Average	62	50

Source: Health Insurance Commission data for New South Wales, Western Australia, Northern Territory, Tasmania and Australian Capital Territory adjusted for estimated fraction of women with an intact uterus (using method of Holman and Armstrong, 1987)

Groups of women can be identified who are less likely to have Pap smears. These include older women, women of low socioeconomic status, women living in rural areas and Aboriginal women. Data from the Victorian Cytology Service show that older women have a lower Pap smear rate than younger women (Mitchell et al, 1987; Health Insurance Commission). A survey of more than 16,000 Pap smears over an eight week period in 1983 in Western Australia found that Pap smear rates were highest in women 20-29 years (340.7 per 1000 women per year) and fell thereafter with age (Armstrong et al, 1986). The frequency of Pap smears was 20% less in rural areas of Western Australia than in Perth. The screening rate in Perth was lower for women of lower socioeconomic status.

Several pilot projects documented lower frequencies of Pap smear tests during the previous three years among women who were older, Aboriginal, or living in rural rather than urban areas. For example, 34% of urban women and 50% of rural women from a sample of 1,925 women surveyed in Queensland reported they had not had a Pap smear in the last two to five years. Sixty-four per cent of 388 Aboriginal women living in remote areas of the Northern Territory who were screened during the pilot project had not had a Pap smear in the last three years. Forty-seven per cent of the women had never had a previous Pap smear.

In contrast to under-screening, there is evidence that a substantial proportion of screened women are being screened very frequently. For example, of women less than 70 years of age who made a claim on Medicare for a Pap smear in April 1988, 20% made a further claim for a Pap smear during the next 12 months (Health Insurance Commission). While a proportion of these repeat Pap smears may have been required for monitoring of women with a previously abnormal Pap smear or repeating an unsatisfactory Pap smear, a significant proportion are likely to have been repeat Pap smears from women with normal results.

Trends in Pap smear rates with time

As Medicare commenced in February 1984 and Pap smear claims are only available from this time, there are no reliable national data for time trends in Pap smear rates. From analyses using the database of the Victorian Cytology Service, it appears that while Pap smear rates substantially increased over the period 1971-86 for women aged less than 35 years, the rates declined over this period for women aged over 50 (Mitchell and Medley, 1987).

Screening histories of women with invasive cervical cancer

An important indication of the adequacy of Pap smear testing can be gained by examining the screening histories of women with invasive cervical cancer. Data addressing this issue are presented in Table 5.4. A majority of the Victorian women who were diagnosed with cervical cancer in 1985 had no screening record with the Victorian Cytology Service during the preceding decade. At that time the Victorian Cytology Service reported 85% of all Pap smears in Victoria. This highlights the need to ensure that women who have never been screened are given priority in recruitment activities.

This type of monitoring should be routine throughout Australia and could be readily performed by State/Territory based cytology registries.

TABLE 5.4 Victorian Cytology Service screening histories of women with invasive cervical cancer in Victoria 1985

No previous Pap smear	153	57%
Previous benign or negative Pap smear	81	30%
Abnormal Pap smear at some preceding time	36	13%
Total	270	100%

Source: Mitchell et al, 1990

5.2.4 How much cervical cancer is currently being prevented?

It is possible to make an estimate of the number of cases of squamous cell carcinoma of the cervix Australia could anticipate in the absence of all screening. This can be done by applying incidence rates for this cancer in a Western European type country which has no screening (Hakama et al, 1986) to the estimated number of women in Australia with a cervix (Holman and Armstrong, 1987). These calculations show that existing cervical cancer screening in Australia is preventing only about 48% of the cancers which would be occurring in the absence of any screening (source: H. Mitchell and Screening Evaluation Coordination Unit). With an estimated 1037 new cases of cervical cancer in 1985 (see Figure 5.1), 700-750 cases of cervical cancer are being prevented each year. For further data and calculations see Appendix 4, Table 5.

5.2.5 Groups involved in the prevention of cervical cancer

Over the 25 years that cervical cancer screening has been available in Australia many professional groups and organisations have become involved. These include:

Service providers

- general practitioners
- gynaecologists
- Family Planning Association
- nurse practitioners
- cytotechnicians
- cytopathologists

Professional bodies:

- Royal Australian College of General Practitioners
- Royal Australian College of Obstetricians and Gynaecologists
- Royal College of Pathologists of Australasia
- Australian and State/Territory Cancer Societies
- Australian Society of Cytology
- Australian Society for Colposcopy and Cervical Pathology
- Public Health Association

Women's groups:

- Women's health groups and networks
- Cancer support groups

Public health professionals:

- Epidemiologists
- Demographers
- Behavioural scientists
- Biostatisticians
- Health economists
- Health educators
- Health planners
- Policy analysts

Funding bodies:

- National Health and Medical Research Council
- Health Promotion Foundations
- Member bodies of the Australian Cancer Society

Australian Institute of Health

Government (Commonwealth, State, Territory).

While each of these groups brings an area of expertise to the debate, no group or organisation has been responsible for a program of cervical cancer screening. The consequences of this unstructured approach to a public health problem are very evident in this report.

5.3 CURRENT FINANCIAL EXPENDITURE BY GOVERNMENTS ON CERVICAL CANCER SCREENING

Table 5.5 provides estimates of current expenditure by governments (both Commonwealth and State/Territory) on cervical cancer screening for women aged 18-69 years, together with the associated expenditure on follow-up for diagnosis and management.

TABLE 5.5 **Current expenditure by all Australian governments on cervical cancer screening for women aged 18-69 years(a)**

	1989 $ millions	1990 $ millions
Screening(b)	59.4	60.6
Follow-up(c) (diagnosis and management)	63.2	64.4
Total	122.6	125.0

Notes:

(a) Expenditures are expressed in 1990 prices.

(b) Expenditure on screening includes only the cost of Pap smear taking and reporting (see text for further detail).

(c) Expenditure on follow-up is based on unit costs per procedure using the Health Insurance Commission 85% rebate levels (see Table 5.7) applied to simplified diagnosis/management regimens (see text for further detail).

5.3.1 Cost of taking and reporting Pap smears

The estimates for the cost of screening are derived by multiplying a unit cost per Pap smear of $34.35 by an estimate of the number of Pap smears taken for "screening" purposes.

The unit cost per Pap smear of $34.35 includes only the cost of screen taking (costed at the Health Insurance Commission (HIC) 85% rebate for a 'B' level general practitioner consultation of $17.85) and the cost of screen reporting (costed at the HIC 85% rebate for pathology item No. SP 2338 of $16.50). The rebate is used rather than the schedule fee or the actual fee charged by medical practitioners, as these financial expenditure estimates are concerned with costs to governments, not the economic cost of services, or the costs to women.

It is acknowledged that there is a lower "OP" (public sector) rate for cervical cytology (on which the 85% rebate is $12.40) as well as the "SP" (private sector) rate used in these estimates. Health Insurance Commission data indicate, however, that 95% of all Pap smears currently taken and itemised to Medicare are at the SP rate. It is also acknowledged that grant funded laboratories are likely to receive less funding on a per Pap smear basis than the $16.50 figure used in these estimates. If grant funded laboratories were being funded at, say $10.00 a Pap smear, then on the basis of their current 20% market share, the total cost estimates for 1989 and 1990 in Table 5.5 might overstate the true cost by one to two per cent.

There is also the question of the appropriate cost to include in situations where a woman visits her medical practitioner for a reason unrelated to screening, but has a Pap smear taken during the visit. It is difficult to gather authoritative data on this issue, but available data suggest that separate appointments tend to be made for the taking of Pap smears. Often general practitioners do not have time to include Pap smears in visits made for other purposes (Bowman et al, 1990) or women prefer to make a separate visit for a Pap smear. The surveys undertaken by pilot projects on financial costs to women, for example, included a question on purpose of visit; 80%-90% of women indicated that they were visiting the clinics for the specific purpose of having a Pap smear taken.

It is also recognised that not all Pap smears are taken by general practitioners (some are taken at higher cost by specialists, while others are taken by nurse practitioners, Aboriginal health workers, etc.). The pilot project data (see Table 7.5) indicate that the cost of Pap smear taking by non-medical practitioners is likely to be equal to, or higher than, the $17.85 estimate. The assumption in these estimates is that the average financial cost to governments for Pap smear taking services (Commonwealth and State/Territory) is approximated by the $17.85 figure used.

The estimate of the number of "screening" Pap smears taken in 1989 was derived from the data in Table 5.6. This table summarises data on the number of women who had at least one Pap smear in a given year, based on those laboratories that bill Medicare (private laboratories and some government laboratories) together with those remaining laboratories which are funded through alternative means (e.g. grant funding). By taking the number of women who had at least one Pap smear in a given year, rather than the total number of Pap smears, a reasonable adjustment can be made for Pap smears taken for diagnostic or management purposes (as these Pap smears would normally follow a previous Pap smear within a 12 month period).

To calculate the number of Pap smears likely to be taken in 1990, the number of screening Pap smears taken in 1989 was converted to age specific participation rates and applied to

Table 5.6 Total number of women aged 15-69 years(a) from whom at least one Pap smear has been taken in a given year between 1985 and 1989.

	1985	1986	1987	1988	1989
Health Insurance Commission	879,230	1,019,550	1,102,738	1,328,438	1,389,843
Grant funded laboratories(b)	367,735	363,808	343,390	338,468	334,466
Total	1,246,965	1,383,358	1,446,128	1,666,906	1,724,309

Notes:

(a) Screening rates are only available by five year age group.

(b) Victorian Cytology Service, Queensland Cytology Service and the Institute of Medical and Veterinary Science (South Australia).

TABLE 5.7 Cost of follow-up diagnosis and management procedures assumed in the cost estimates of current financial expenditure by Australian Governments on cervical cancer screening

Service or procedure	HIC Item No.(a)	HIC Fee(a)	85% Rebate level(a)
		($ per service)	
Diagnosis			
General practitioner consultation	23	21.00	17.85
Cytology report on Pap smear	2338(b)	19.40	16.50
Specialist visit	88	54.00	45.90
Colposcopy and punch biopsy	6415) 6411)	60.00	51.00
Anaesthetic consultation and procedure (if needed)	510S) 825)	77.60	66.00
Histopathology report	2327	89.00	75.65
Management			
Colposcopy/biopsy/diathermy	6483	128.00	108.80
Laser	6303	172.00	152.00
Conisation	6430	110.00	93.50
Anaesthetic consultation and procedure treatment	510S) 825)	77.60	66.00
Day care hospitalisation for treatment		110.00	
Review			
Specialist review at 3 months	94	27.00	22.95
- Pap smear	2338 SP	19.40	16.50
- Colposcopy	6415	40.00	34.00
General practitioner review at 12 mths	23	21.00	17.85
- Pap smear	2338 SP	19.40	16.50

Notes:

(a) Medicare Benefits Schedule Book (effective 1 May 1990), Commonwealth Department of Community Services and Health

(b) Private sector rate for Medicare rebate.

the Australian Bureau of Statistics Series C population projection for 1990. No allowance has been made for any increase in participation in 1990 compared with 1989.

5.3.2 Cost of follow-up diagnosis and management

Follow-up diagnosis and management costs of screen detected abnormalities vary depending on the method and place of treatment. Estimates of financial expenditure by governments on follow-up diagnosis and management were based on unit costs per procedure using the Health Insurance Commission 85% rebate levels (see Table 5.7) applied to simplified diagnosis/treatment regimens. The probability that women followed up would have various combinations of procedures was estimated from pilot project and Victorian Cytology Service data (see Figure 5.2). This yielded a weighted average cost of $426 per woman followed up. This is a very conservative estimate of the cost of management and is considerably less than other estimates which have been made (e.g. $700 per patient by Free et al, submitted for publication). Table 7.14 shows the impact on the cost-effectiveness of an organised screening program of variations in the estimated cost of management.

The follow-up rates were estimated by five year age group, also using pilot project and Victorian Cytology Service data (see Table 5.8).

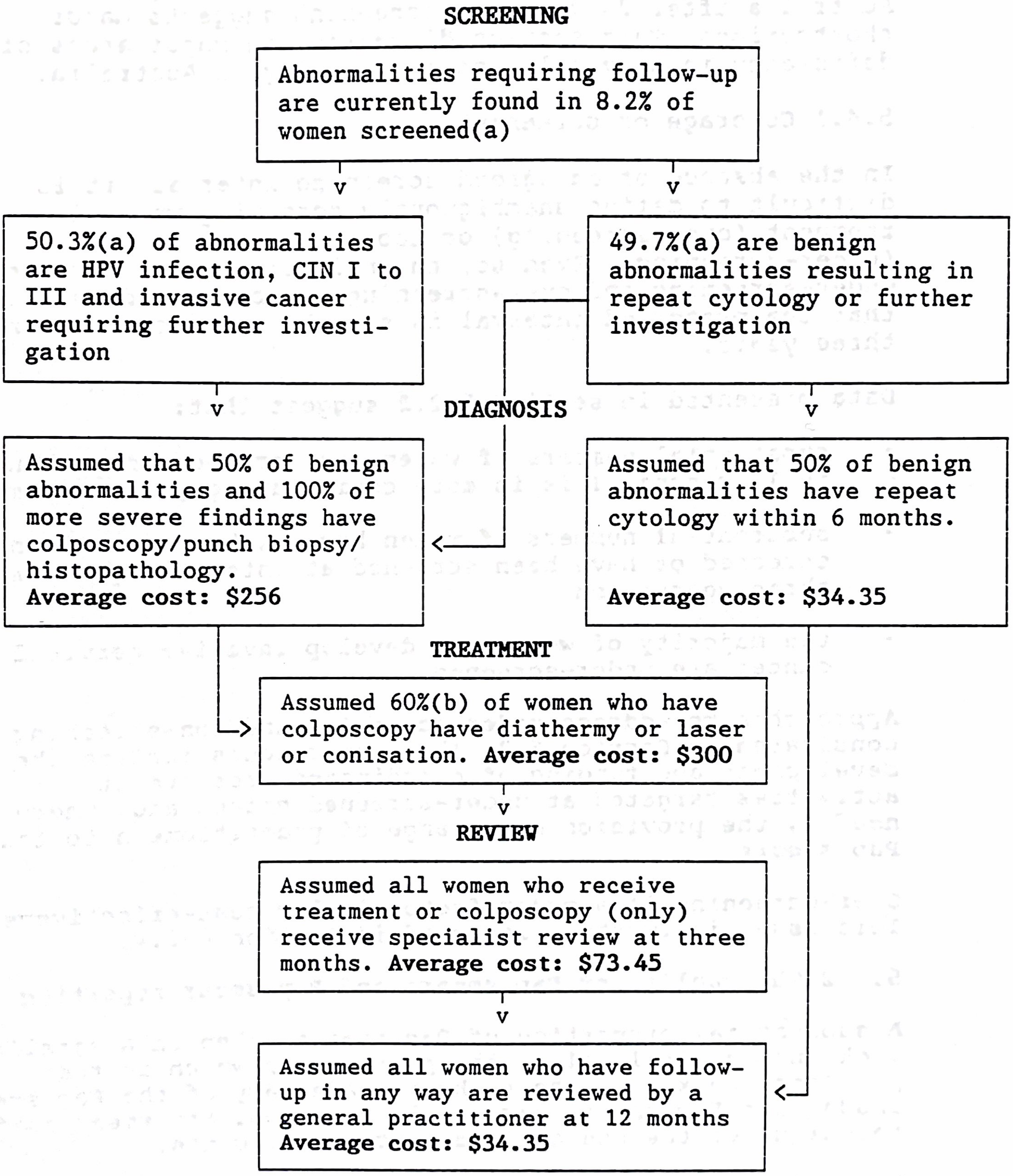
TABLE 5.8 **Follow-up rates for women who have participated in cervical cancer screening**

Age (years)	Estimated % of women receiving further assessment(a)
18-19	11.9
20-24	11.9
25-29	10.3
30-34	8.3
35-39	7.8
40-44	7.1
45-49	6.9
50-54	5.3
55-59	4.4
50-64	5.1
65-69	4.8
Total	8.2

Note:

(a) Based on data from the pilot projects and the Victorian Cytology Service.

FIGURE 5.2 Simplified follow-up regimens assumed in the cost estimates, together with the estimated proportion of women who will receive various combinations of procedures



Abnormalities requiring follow-up are currently found in 8.2% of women screened(a)

50.3%(a) of abnormalities are HPV infection, CIN I to III and invasive cancer requiring further investigation

49.7%(a) are benign abnormalities resulting in repeat cytology or further investigation

Assumed that 50% of benign abnormalities and 100% of more severe findings have colposcopy/punch biopsy/histopathology. Average cost: $256

Assumed that 50% of benign abnormalities have repeat cytology within 6 months.

Average cost: $34.35

Assumed 60%(b) of women who have colposcopy have diathermy or laser or conisation. Average cost: $300

Assumed all women who receive treatment or colposcopy (only) receive specialist review at three months. Average cost: $73.45

Assumed all women who have follow-up in any way are reviewed by a general practitioner at 12 months Average cost: $34.35

Notes:

(a) Based on data from pilot projects and the Victorian Cytology Service.
(b) Based on data from the Upper Spencer Gulf (Iron Triangle) pilot project in South Australia, and includes data from the public screening clinics and general practitioners.

5.4 CURRENT SHORTCOMINGS OF CERVICAL CANCER SCREENING

International studies have shown that 90% of squamous cell carcinomas are preventable. The fact that only half of the preventable cases of cervical cancer are being prevented in Australia after 25 years of screening suggests major shortcomings. This section discusses the major areas of deficiency in cervical cancer screening in Australia.

5.4.1 Coverage of screening

In the absence of an agreed screening interval, it is difficult to define unambiguously screening which is too frequent (over-screening) or too infrequent (under-screening). Even so, an indication of the problems of under-screening and over-screening can be gauged by assuming that the preferred interval is somewhere between one and three years.

Data presented in section 5.2.2 suggest that:

- substantial numbers of women are screened more than once in 12 months. This is more common among younger women;
- substantial numbers of women have either never been screened or have been screened at intervals greater than three years; and
- the majority of women who develop invasive cervical cancer are under-screened.

Approaches to address under-screening and non-screening are considered in Section 6.3. These approaches include the development and funding of coordinated recruitment activities targeted at under-screened groups and, where needed, the provision of a range of practitioners to take Pap smears.

Over-screening is a major factor in low cost-effectiveness. This issue is further discussed in Section 6.2.4.

5.4.2 The quality of Pap smears and Pap smear reporting

A substantial proportion of Pap smears taken in Australia lack endocervical cells, the presence of which is the principal marker of the technical adequacy of the Pap smear. Inadequate Pap smears may result from poor Pap smear taking technique or the use of inadequate instruments.

There is wide variation in the way laboratories report abnormal Pap smear results and in the recommendations made for management. In particular, there is considerable variation in the reporting of so-called 'minor' abnormalities. Among Western Australian laboratories, the proportion of Pap smears reported as having minor abnormalities varied from 0.8% to 20.7% (Armstrong et al, 1986). The lack of uniform terminology in the description of abnormalities produces confusion among referring practitioners, and may lead to inappropriate follow-up of women with abnormalities.

To ensure high quality screening, comprehensive quality assurance and monitoring are required. One way of promoting accurate Pap smear reporting is to accredit all laboratories reporting screening tests. As discussed in section 6.5, there are National Association of Testing Authorities' accreditation criteria for cytology laboratories as well as the Royal College of Pathologists of Australasia quality assurance program in cytology. However, these accreditation criteria and quality assurance activities are limited in scope and fail to address key issues in ensuring high quality reporting. Measures to address these issues are also discussed in Section 6.5. Professional education is discussed in Section 6.8.

5.4.3 The interval between rescreening

Both within Australia and in other countries there is a large variation in the recommended interval for screening women. To address this problem, the Australian Cancer Society held a consensus conference in July 1988 with funding from the "New Initiatives for Women" budget.

While the consensus panel unanimously agreed to a set of recommendations, these have not been widely accepted. The continuing lack of agreement on the recommended rescreening interval remains a major barrier in planning and implementing an organised approach to cervical cancer screening in Australia. This issue is further discussed in Section 6.2.4.

5.4.4 The management of women with abnormal Pap smears

In Australia during 1990, around two million Pap smears will be taken, and in the private sector, 100,000 colposcopies and 75,000 biopsies and diathermies will be performed. Approximately 700-750 cases of invasive cervical cancer will be prevented.

Currently there are no empirically based guidelines on the indications for colposcopy, biopsy and diathermy of women with minor abnormalities on their Pap smears. This area was considered to be outside the terms of reference for the "New Initiatives for Women" budget which funded the cervical cancer screening pilot projects. There is an urgent need for a review and discussion of all available evidence in this area, preferably sponsored by an authoritative body such as the National Health & Medical Research Council or the Australian Cancer Society, and involving the Royal Australasian College of Gynaecologists and the Australian Society of Colposcopy and Cervical Pathology.

5.4.5 The decline of public sector laboratories

In most areas of Australia, reporting of Pap smears is carried out in both public and private laboratories. As well as providing a screening service, public laboratories also train most cytotechnicians and cytopathologists, and conduct most of the research done in Australia.

Current funding arrangements favour private laboratories. Grant funded laboratories receive even less than the OP (public sector) rate. This has resulted in declining throughput in such laboratories (see Table 5.6) and potentially jeopardises their teaching and research functions which benefit all Australians. A workforce study funded from the "New Initiatives for Women" budget has shown that Australia has sufficient numbers of cytotechnicians, but inadequate numbers of cytopathologists. (See summary in Volume 2.)

Public laboratories need adequate funding to maintain a sufficient volume of tests and to fulfil their training responsibilities.

5.4.6 Monitoring cervical cancer screening

Monitoring the performance of the various components of the screening pathway in relation to the resources employed is fundamental to an organised approach. This monitoring applies to recruitment, Pap smear taking and reporting, and the management of women with abnormal Pap smears. This will enable resources to be used most effectively, identify problem areas requiring particular attention and determine effective strategies and techniques which could be widely adopted. Such monitoring requires a budget and recognition of the central importance of the data collected to show that the screening program is accountable for its use of limited health dollars.

Currently the little monitoring which is undertaken in Australia is fragmented and under-resourced. An important initiative to overcome these problems has been the establishment of cervical cytology registers in Victoria and Western Australia (see Section 6.10). Monitoring is discussed more fully in Section 6.9.

5.4.7 Cost-effectiveness of the current approach

In Section 5.3 conservative estimates are presented of the current financial expenditure by Commonwealth and State/Territory governments in funding the present approach to cervical cancer screening. Given the shortcomings of the current approach outlined above, the question has to be asked whether this current expenditure of $125 million represents value for money in the use of limited health funds.

Further, as participation in screening programs also involves substantial costs to women and their families, (for example, the gap between the fees charged by medical practitioners for services and the Medicare rebate, time and travel costs, child-minding expenses, co-morbidity and anxiety) the concept of cost needs to be expanded beyond financial expenditures by governments to include the costs to women in attending the services provided. If the current costs to women of approximately $37M per annum are added to the $125M being paid by governments for service provision, the current approach to cervical cancer screening is costing approximately $162M per annum.

In Chapter 7 of this report a full analysis is presented of these issues, including the cost-effectiveness of the current and recommended approaches to cervical cancer screening, set against the cost-effectiveness of alternative health programs. It is sufficient to note here that the current approach to cervical cancer screening has a cost-effectiveness of $44,654 per life year saved. By adoption of the measures recommended in this report, it is estimated that this cost-effectiveness could be improved to $30,782 per life year saved. Moreover, this improvement can be attained while simultaneously improving access for high risk groups (including those women in rural and remote areas of Australia) thereby achieving a greater impact on preventing cervical cancer.

5.4.8 Conclusion

These shortcomings are largely attributed to the historic development of cervical cancer screening in Australia, in which responsibility for screening has been with the individual clinicians, without any systematic targeting of the population or monitoring of the effects of screening efforts. Solutions to many of these problems are provided by the proposal to introduce an organised, population-based approach to cervical cancer screening, as presented in subsequent chapters.

5.5 NATIONAL TARGETS FOR CERVICAL CANCER AND FOR SCREENING

In implementing population-based screening, it is important that there be targets against which progress can be compared. The targets identified by the Australian Health Ministers' Health Targets and Implementation (Health for All) Committee (1988) are as follows:

- to reduce the death rate from cervical cancer by 30% or more by the year 2000;
- to increase triennial participation in cervical cancer screening to 50% or more of women aged 20-69 years by the year 1990, to 75% or more by the year 1995 and to all but a negligible number by the year 2000;
- to establish organised population based cervical neoplasia screening programs in each State and Territory by the year 1990.

Clearly the last goal has not been achieved. Nevertheless, these and similar goals provide an important focus for cervical cancer screening programs as well as identifying the most important performance measures for purposes of monitoring.

6. COMPONENTS OF AN ORGANISED APPROACH TO CERVICAL CANCER SCREENING

6.1 OVERVIEW

An organised approach to cervical cancer screening requires a mechanism to ensure that all facets of the screening pathway are adequately addressed. The following are essential components of an organised approach to cervical cancer.

Recruitment

Recruitment covers activities involved in making women aware of the screening program and encouraging them to participate regularly in screening.

Pap smear taking

Different screening services should be made available in order to provide women with a choice of Pap smear takers and service type. This is intended to increase the proportion of women who attend for screening.

Pap smear reporting and notification of results

Cytology laboratories are responsible for processing and reporting Pap smears. Frequently, the report of the Pap smear also makes recommendations on any further management or treatment that may be required. The laboratories notify practitioners of the results of the Pap smears. Practitioners then notify women of their Pap smear results.

Management of women with abnormal Pap smears

Management of women with abnormal Pap smears may involve repeating the Pap smear, treatment of any infection detected by screening, or referral for colposcopy. Colposcopy may result in biopsy and ablative treatment of CIN. For extensive disease, cone biopsy or hysterectomy may be required.

Quality assurance and monitoring

An important mechanism for ensuring that high quality services are provided is ongoing monitoring and evaluation of the following aspects of screening:

- screening performance and effectiveness
- women's views about services
- cost.

Accreditation

Accreditation of cytology laboratories is required to ensure that highest quality services are provided. The process should ensure that cytology laboratories meet existing accreditation standards as well as ongoing accreditation standards. Existing accreditation standards relate to issues such as qualifications and training of Pap smear readers and the number of Pap smear readers available to meet the envisaged workload. Ongoing accreditation should relate to issues such as throughput, participation in quality assurance activities and achievement of performance standards in day to day work.

Policy

The development and review of policy is required to ensure that the guidelines within which screening programs operate provide a framework for maximising the acceptability, equity, quality and cost-effectiveness of the total program.

Coordination

Coordination ensures that all components of the screening program are properly established, that there is appropriate communication between these components and that resources are distributed so as to maximise the effectiveness of the program.

Funding

Mechanisms are required for funding the screening program which are supportive of (or at least neutral towards) its principal objectives.

Training

Specialised training is required for Pap smear takers (doctors and nurses), Pap smear readers (cytotechnicians and cytopathologists) and gynaecologists who treat cervical abnormalities. The range and availability of training resources varies across States and Territories. Organised cervical cancer screening may require the development of resources for training. Particular attention may be needed for personnel in rural areas.

Research

Ongoing research is essential in order to develop improved ways of providing screening (especially intervention trials of recruitment methods) and managing screen detected abnormalities.

6.2 SCREENING POLICIES

As discussed in Section 5.4, a major deficiency in cervical cancer screening in Australia is the lack of uniform policies on such issues as the ages to start and stop screening, the need for screening following hysterectomy and the recommended screening interval. Key policy issues for a national cervical cancer screening program are:

- which women should be screened?
- how often should such women be screened?

The recommendations of the July 1988 Consensus Conference were as follows:

1. Women who have not had a Pap smear should be the first priority group for cervical cancer screening programs.
2. The target group for cervical cancer screening is all women.
3. Screening should commence at 18 years.
4. Screening should stop at 65 years providing all previous Pap smears have been normal.
5. Accepting that there would be a greater relative protection with more frequent screens, three yearly screening is recommended on economic grounds, providing two annual Pap smears are normal.

6.2.1 Risk factor approach

Many risk factors for cervical cancer have been documented (See section 5.1.3). The use of risk factors to determine which women should be screened and at what frequency is of limited benefit. Some risk factors apply to large proportions of the community (e.g. smoking), some are perceived as stigmatising (e.g. infection with the sexually transmitted Human Papilloma Virus), and women without any identifiable risk factors also develop CIN or cancer.

However, knowledge of sociodemographic risk factors is useful in program development to define the groups of women who are less likely to be screened and for whom the greatest efforts should be made to achieve regular participation in screening. This is appropriate because the rate of cervical cancer in such groups of women is higher than in the general population.

While the known risk factors may help identify groups of women who have higher rates of cervical cancer, there is no evidence that the risk factors define a group of women who develop cancer quickly. Thus risk factor profiles of population groups cannot be used to define a rescreening interval.

6.2.2 Age to start screening

There are two possible options - to either nominate a chronological age, or to relate the commencement of screening to the commencement of sexual activity. While the former is easier for educational campaigns, clinicians often prefer the latter, recommending a Pap smear be taken within 12 months of the commencement of sexual intercourse.

The Consensus Conference convened by the Australian Cancer Society in Melbourne in July 1988 recommended that the first Pap smear should be taken at age 18 years. This recommendation presumes that virgins aged 18 years and over will be informed by their practitioner that they do not need screening.

However, there are concerns about the poor cost-effectiveness of screening young women. Best available estimates of the cost-effectiveness of screening women at different ages are presented in Section 7.3. In view of these estimates, the Committee recommends that a consultative process and a review of the evidence be undertaken to determine whether the recommended age for commencement of screening should be raised from 18 years.

It should be noted that an estimated eight per cent of new cases of cervical cancer occur in women under age 30 years (see Figure 5.1), although three quarters of these occur among women aged 25 to 29 years.

6.2.3 Age to stop screening

The same Consensus Conference recommended that screening should stop at 65 years of age, providing all previous Pap smears have been been normal. Implicit in this recommendation is the assumption that the woman should have had previous Pap smears.

Given the increasing life expectancy of women and the fact that the highest incidence of cervical cancer in Australia is among women aged 60-69 years, the Committee recommends continuing screening up to 70 years of age. Screening the 65-69 year age group may result in an additional 124 cancers being detected per annum and would improve the cost-effectiveness of a national screening program (see Table 7.10). It seems reasonable to cease screening at this age as a series of previous negative tests is associated with very low risk of developing cervical cancer. However, there should be no impediment to women being screened beyond this age if they so wish.

6.2.4 Rescreening interval

The hesitations of clinicians about the recommendations of the Consensus Conference in relation to rescreening interval (see above) appear to derive from the following:

1. The lack of a reminder system

Many clinicians are concerned that currently, in the absence of a reminder system, a recommendation for rescreening in one year translates into many women being rescreened two or three years later. There is concern that a recommendation for rescreening in two or three years may translate into rescreening every four to six years.

2. Accuracy of screening as currently delivered

Many clinicians are concerned by the level of accuracy of screening cytology as currently performed in Australia. Anxieties about under-calling of abnormalities and false negative reports often result in recommendations for frequent rescreening as a compensatory measure.

3. Rapid onset cancer

Some clinicians are concerned that a new, aggressive form of cervical cancer may have emerged recently. These concerns arise from cases noted by individual gynaecologists or gynaecology units. These concerns have not been able to be addressed at the State/Territory level to the satisfaction of clinicians due to the fragmentation of screening data into many laboratories. As discussed in Section 5.1.2, data currently available do not support this suggestion.

Each of these areas of concern can be addressed in ways other than recommending a short rescreening interval. For example, a comprehensive reminder system can be introduced and monitoring data can be used to determine the frequency at which women are screened, the degree of serious inaccuracy in cytology reporting and the size of the problem of rapid onset cancer. For example, the Victorian Cervical Cytology Registry will be able to address each of these issues. However, it is unlikely that Victorian data on accuracy and rapid onset cancer will satisfactorily address these issues for the clinicians of other States/Territories. Victoria is considered to be atypical in that a majority of Pap smears are reported in one large laboratory.

In the absence of new initiatives specifically targeted in each State/Territory to address the clinicians' concerns, it is considered unlikely that they will accept any recommendation other than annual screening. The current policy of the Royal Australian College of General Practitioners is that all women should have an annual Pap smear commencing within one year of the commencement of sexual intercourse. The College further recommends that after consideration of the relative risks to the individual woman, she and her physician may choose to increase the interval between Pap smears provided this interval does not exceed three years.

Some clinicians have expressed the view that they feel the need to remain consistent in their advice to women. Thus if they have previously advocated an annual screening interval, they should continue to advise annual Pap smears so as not to confuse women.

Because of the lack of monitoring data for screening which has been performed in Australia to date, it is not possible to present estimates of the proportion of cancers which could be prevented with different screening intervals other than by utilising overseas data. This lack of comprehensive local data was a major difficulty at the Consensus Conference in 1988. It remains a difficulty today.

For example, the International Agency for Research on Cancer study of screening in centrally organised programs estimated that among women aged 35-64 years, 90.8% of squamous cell cancers of the cervix could be prevented with three yearly screening, 92.5% with two yearly screening and 93.5% with annual screening. The International Agency for Research on Cancer study principally utilised evidence from screening performed during the 1960s and 1970s.

If screening is as effective in the 1990s, if the same level of benefit applies to younger women, and if Australia had a centrally organised program, then three yearly screening of women aged 20-69 years would prevent 1415 cases of squamous cell carcinoma annually. Two yearly screening would prevent an additional 26 cancers each year and annual screening a further 16 cancers each year. While different estimates of the preventability will result in different estimates of the number of cancers prevented, it is unlikely that the magnitude of the numbers will alter substantially.

By 1995, the financial cost to governments of a centrally organised program has been estimated to be $104 million per annum for a three year rescreening interval, $153 million per annum for a two year rescreening interval and $305 million for a one year rescreening interval (see Tables 7.1 and 7.2 in Chapter 7).

The Steering Committee agreed to a recommendation for a two year interval conditional upon the operation of comprehensive reminder systems and of systems to monitor the accuracy of screening. This recommendation must be viewed as a package. These two conditions are vital to the recommendation on screening interval.

This agreement was a compromise position which should be acceptable to professional and community groups. It is acknowledged that no further data on the relative protection associated with different screening intervals have been forthcoming since the Consensus Conference, but that for practical reasons associated with recruitment initiatives and for maximising cost-effectiveness, uniformity is highly desirable.

The Commonwealth should accept the recommendation as an interim policy for three years of steady-state operation, after which time it should be reviewed in the light of the monitoring data and of the screening practices for which the

Commonwealth is meeting the major cost. As implementation of the comprehensive reminder system and of the monitoring system will take up to two years to complete, the review should be in 1995 at the earliest.

The Steering Committee suggests that new funding mechanisms to the States/Territories (for recruitment, reminder systems and monitoring systems) be conditional on the State/Territory utilising the recommendation outlined above for public and professional education.

If at the end of the three year period of steady state operation, a substantial proportion of women are being screened more frequently than every two years, the Commonwealth may elect to restrict the frequency at which it will reimburse women for the cost of screening. The Committee envisages a number of problems with any restriction in payout (resistance from women and practitioners, social inequity, administrative difficulties) and feels that in the first instance the voluntary suggested approach suggested above is preferable. (See Section 7.5 for further examination of possible options.)

Where a central reminder system is established, it would be undesirable for reminder letters to be automatically sent to women at two years. Centralised reminder systems, such as from a registry, should act as a back-up to any reminder services offered by clinicians and by laboratories. Much useful information for reconsidering the policy will be available from women who are screened during the third year after a previous test.

6.3 RECRUITMENT FOR SCREENING

The effectiveness of cervical cancer screening programs on a population basis is closely related to the proportion of eligible women who are regularly screened. Given the under-screening of some population groups in Australia, it is essential to identify factors which encourage women to attend screening and those which act as barriers to attendance. Having identified these factors and their degree of significance for under-screened groups of women, recruitment strategies can then be formulated to target identified problems and thereby maximise attendance at screening.

This Section presents the options for recruiting women to cervical cancer screening in the light of pilot project experience. Summary descriptions of the pilot projects are presented in Volume 2 of this report.

6.3.1 Barriers to cervical cancer screening

A number of pilot projects carried out research to identify factors that contributed to women's perception and understanding of cervical cancer screening and influenced their attendance at screening. The Queensland Cervical Cancer Screening pilot project undertook a Statewide community survey of 1925 women to assess knowledge and attitudes about screening and perceived barriers to participation. This coincided with the start of a Statewide cervical cancer screening mass media promotion. A post-intervention survey was also conducted in rural areas of Queensland where Pap smear clinics were provided. After the mass media promotion, 627 rural women were interviewed. Similar surveys by the South Australian, New South Wales and Western Australian cervical cancer screening pilot projects sought information from 1058 women resident in the Upper Spencer Gulf region of South Australia, 775 women resident in six rural towns in New South Wales and, in Western Australia, 402 white women and 36 Aboriginal women from two rural communities.

In addition, the New South Wales Women's Health Nurse evaluation project and the Australian Capital Territory pilot project surveyed women who attended special clinics staffed by specially trained nurses. There were 1403 women in the New South Wales survey, (439 urban women of whom 83% were from Sydney, and 964 rural women), and 143 in the Australian Capital Territory survey. As these women self-selected to attend special clinics staffed by nurse practitioners, and presumably had particular reasons for doing so, their responses are not representative of all women, only of those women who choose to attend such clinics.

The results of these community and client surveys are presented in Table 6.1. Pilot projects used different

TABLE 6.1 **Women's knowledge, attitudes and beliefs about cervical cancer screening (all figures are percentages)**

	Community surveys						Client surveys		
	QLD		SA Upper Spencer Gulf	NSW rural towns	WA		NSW women's health nurses		ACT Pap smear clinics
	State-wide n=1925	Rural towns(a) n=697	n=1058	n=775	Rural n=402	Abor-iginal n=36	Sydney n=439	Rural n=964	n=210
KNOWLEDGE									
Know Pap smears can detect cervical cancer	92			97	85	<30			
Know Pap smears can detect early signs of cervical cancer	96		94	99					
Know Pap smears help prevent cervical cancer	39								39
Think cervical cancer is just as likely even if women have regular Pap smears	29								
Think Pap smears should begin when:									
- Women become sexually active	34			40					56
- Women begin contraception	10								21
Know Pap smears are needed after menopause	64			80					
Don't know Pap smears are needed regularly	6		11(c) (NESB=17(i) other=9)	6	1	54(d)	6(g)	5(g)	
needed regularly Don't know where to go for Pap smears	8			3(c)			5(g)	2(g)	10
ATTITUDES									
Cervical cancer screening is worthwhile	79			90					
Would experience anxiety about test	6								
Would experience anxiety about result	13	0.3	41(b) 16(d)	7(c) 12(e)					
Don't want to know if cervical cancer is present/ already have enough health problems	4		9 (NESB=18(i) other=7)	3(c)	3(d)				6

TABLE 6.1 continued

	Community surveys						Client surveys		
	QLD		SA Upper Spencer Gulf	NSW rural towns	WA		NSW women's health nurses		ACT Pap smear clinics
	State-wide n=1925	Rural towns(a) n=697	n=1058	n=775	Rural n=402	Abor-iginal n=36	Sydney n=439	Rural n=964	n=210
ATTITUDES (continued)									
Think Pap smears are embarassing	23 45(g)	2	60(b) 27(c) 42(d)	31(c) 24(e)	8(c)	39(d)	6(g)	7(g)	19
Think Pap smears are painful	11		10(b) 6(d)	4(c) 8(e)					8
Think Pap smears are uncomfortable	11		35(b)		2(c)				
BELIEFS									
Regular Pap smears will save my life	92		92	98					
Believe cervical cancer is mod-completely curable	87		80		85				
Believe cervical cancer is mod-completely preventable	75			68					79
Believe they do not need Pap smears and/or are not at risk	33(j)/ 56(f)	24(j)	32(d)	49(f)					
PERCEIVED CHARACTERISTICS OF PAP SMEAR TAKERS									
Would be influenced by doctor's advice	77			98					38
Dr said Pap smears not necessary or did not offer Pap smear	19		13(c)	19(c)			11(g)	9(g)	
Dr appears too busy	24		11(d)		2(c)				
Prefer a female doctor/nurse	38/5	53/1		36		89	21(g)	64(h)	69
Prefer a male doctor	10	3		14		0			0
No preference for doctor or nurse				24(k)					66
No preference for sex of doctor/nurse	52	42		50		11			29
Lack of female Pap smear taker	11			13(c)	2(c) 7(d)			12(g)	16

TABLE 6.1 continued

	Community surveys						Client surveys		
	QLD		SA Upper Spencer Gulf	NSW rural towns	WA		NSW women's health nurses		ACT Pap smear clinics
	State-wide n=1925	Rural towns(a) n=697	n=1058	n=775	Rural n=402	Aboriginal n=36	Sydney n=439	Rural n=964	n=210
OTHER									
Forget to have regular Pap smears	36		31(c)	8(c)	15(c) 10(d)		8(g)	6(g)	1(g)
Not enough time to have regular Pap smears	16			13(c)	13(c) 3(d)				1(g)
Pap smears cost too much	10			3(c)			2(g)	1(g)	1(g)
Difficulty in getting to have Pap smear due to distance, lack of transport or lackof child care	12		2(c)	1(c)				2(g)	6(g)
Other - not specified			7(c)	12(g)				7(g)	

Notes:

(a) Post-campaign survey.
(b) Based on those women who reported problems with last Pap smear.
(c) Based on women who had no Pap smear in the last three years.
(d) Based on women who have never had a Pap smear.
(e) Based on women who had been screened in last three years.
(f) Percentage of women who reported that it was "not very likely" or that it was "very unlikely" that they would suffer from cervical cancer at some time in their lives.
(g) Barriers reported by women who had never been screened or had not been screened in last two years.
(h) Percentage of women who stated that it was "very important" to them that the smear was taken by a female.
(i) NESB designates women from a non-English speaking background.
(j) Based on women who do not intend to have a Pap smear or are unsure.
(k) Sixty eight per cent of women prefer a doctor and 8% a nurse.

questionnaires and survey methodology, so results reported are not always directly comparable, but they do indicate women's attitudes to the issues raised.

Factors which were identified as inhibiting women from having Pap smears fell into three broad categories:

1. women's knowledge, attitudes and beliefs about cervical cancer screening;

2. women's perception of Pap smear services; and

3. other reasons, such as forgetting or inadequate time.

Eighty-five per cent to 97% of women demonstrated some knowledge of the reasons for having Pap smears, with the exception of rural Aboriginal women, whose knowledge was very limited. Most knew that Pap smears could detect early cervical cancer. However, around one third of women were not aware that early detection helped prevent cervical cancer. Detailed knowledge about when to commence and finish cervical cancer screening was also unsatisfactory. However, women were well informed about the need to have regular Pap smears and about places where screening could be undertaken.

Around 80% of women held a favourable attitude towards screening and felt it worthwhile. However, perceptions of the test as embarrassing, uncomfortable, painful or anxiety provoking by up to 40% of women are likely to deter some of these women from having regular Pap smears.

Beliefs that cervical cancer screening is life saving were expressed by over 90% of women. Well over two thirds of women believed cervical cancer was curable or preventable. Of some concern however is the observation that 24-56% of women did not believe they were personally at risk of cervical cancer. Nineteen per cent of women surveyed in the Upper Spencer Gulf who had never had a Pap smear believed Pap smears were unnecessary. (This included women who had had hysterectomies.)

A number of factors relating to the practitioner also influenced women's perception of screening. Seventy-seven to ninety-eight per cent of women said they would be influenced to have a Pap smear by advice or encouragement from their doctor. Nine to nineteen per cent of women would not have a smear if the doctor did not suggest or advise one. Whilst up to 50% of women in the community surveys had no preference for the gender of the smear taker, more women expressed a preference for female rather than male smear takers. Women who actually attended Pap smear clinics staffed by female nurses not surprisingly had a stronger preference for female smear takers than women from the community surveys (64-70% compared with 38-53%). Relatively few women reported that the lack of a female practitioner prevented them having a Pap smear (2%-16%). In a small survey in Western Australia 90% of rural Aboriginal women expressed a preference for female Pap smear takers.

The community surveys found that up to one third of women reported "forgetting" as a reason for not having regular Pap smears. Relatively few women reported lack of time, cost, transport difficulties or lack of child care as problems associated with having smears (1-10%). In the surveys of women attending special Pap smear clinics, the corresponding percentages of women reporting these barriers were even lower.

6.3.2 Overcoming barriers to screening

In addition to identifying factors which prevent women from attending cervical cancer screening, the Queensland State-wide community survey also examined possible avenues for remedial action (Cervical cancer screening: A survey of Queensland women - Queensland pilot project). Women were asked to choose from a list of those factors which would make Pap smears more acceptable and encourage more women to have regular Pap smears. Over two thirds of women thought that measures such as public education about Pap smears, letters from medical practitioners or a statewide system to remind women to have Pap smears, medical practitioners suggesting Pap smears to all women attending their surgeries for other purposes and making the Pap smear procedure as comfortable and unembarrassing as possible would increase the number of women screened. These findings were strongly supported by the survey of New South Wales rural towns. These results are discussed further in the following section.

Strategies to increase cervical cancer screening rates

The survey findings presented above suggest a number of avenues by which the uptake of screening may be increased:

1. Improved opportunistic screening by increasing initiation of Pap smears by medical practitioners.

2. Additional and more extensive coordinated community and media-based health education programs.

3. Individualised invitations to women to attend screening.

4. The provision of supplementary services for taking Pap smears (discussed in Section 6.1.4).

1. Initiation of Pap smears by medical practitioners

Currently, most Pap smears in Australia are taken by general practitioners. An audit of Pap smears taken during an eight week period in Western Australia in 1983 showed that general practitioners took 63% of all Pap smears. On average, female general practitioners took twice as many Pap smears as male general practitioners (Armstrong et al, 1986). Fifty per cent of women attending women's health nurses in Sydney, 69-79% of rural women surveyed in New South Wales and 83% of rural Queensland women surveyed had their last Pap smear taken by a general practitioner; 20% and 7-10% in the respective projects were taken by a gynaecologist (New South Wales women's health nurse evaluation project, New South Wales cervical cancer screening pilot project).

General practitioners have many opportunities to promote Pap smears to women. Data from the Australian Bureau of Statistics Health Survey indicate that approximately 80% of women visit general practitioners at least once in any one year (Australian Bureau of Statistics, 1986). On average, women aged 20 years visit their general practitioner four times a year, increasing to around six visits annually by age 60 years (Australian Institute of Health, 1988).

The central role of general practitioners in cervical cancer screening is reflected in data from the pilot projects and previous research. A community survey in Newcastle in 1988 found that 91% of 1125 women who had not had a Pap smear in the last three years said they would have a Pap smear if their general practitioner invited them to (Bowman et al, 1988). Of 258 women surveyed in the Upper Spencer Gulf (South Australia) pilot project, 26% nominated doctors as the best source of information on Pap smear screening, second only to electronic and printed media (56%) (South Australia pilot project). In the Queensland pilot project community survey, 69% of 1925 women surveyed said they would find Pap smears more acceptable if they were suggested by a doctor, 77% reported that they would have a Pap smear if it was suggested by a doctor, and 70% preferred a doctor to take the Pap smear. (Queensland Cervical Cancer Screening Evaluation Project, 1989 - Queensland pilot project). Similar results were found in a post-intervention survey of 775 women resident in the six rural communities which were targeted by the New South Wales Cervical Cancer Screening Evaluation pilot project. It was found that 68% of women would prefer a doctor to perform their Pap test and over 90% would probably or definitely have a Pap smear if advised or invited by their doctor (New South Wales cervical cancer screening pilot project).

The effectiveness of the efforts of general practitioners to increase participation in screening is indicated by a study of women aged 40 years and over showing that 50% of who were overdue for screening had a Pap smear in response to their general practitioner's invitation (Cockburn et al, 1990). Another study conducted with male general practitioners selected at random from inner metropolitan Sydney suggests that cervical cancer screening within routine medical consultations is effective and acceptable to both women and practitioners. Specific interactional skills to increase women's acceptance of opportunistic screening were tested on a consecutive sample of patients presenting for unrelated health problems The majority of women consented to cervical cancer screening in the same consultation in which their screening status was identified (Ward et al, submitted for publication).

Experience from the South Australian and Australian Capital Territory pilot projects, which encouraged opportunistic screening by general practitioners, found that general practitioners were successful in increasing screening among women attending their surgeries. Even though general practitioners are in a strong position to promote cervical cancer screening, the potential of this method of recruitment is not being fully realised. Eighty three per cent of women unscreened in the last three years in the Newcastle survey reported attending a general practitioner during the preceding twelve months (Bowman et al, 1988), while 47% of women in the Queensland survey reported that their doctor had not suggested a Pap smear.

Integration of general practice initiated screening with a more systematic invitation system is required. This could be achieved by encouraging general practitioners to offer cervical screening and to establish reminder systems using the recommended interval of two years, with a back-up State/Territory registry reminder system as a safety net for inviting women who have not been screened within three years.

2. Community and media based health education programs

The introduction of an organised approach to cervical cancer screening should be accompanied by appropriate public education. Education and information about cervical cancer screening can fulfil several functions, including providing information about the reasons for Pap smears, the availability of Pap smear services, and reminding or prompting women to have a Pap smear. Education and information can also address concerns about possible discomfort or pain and anxiety about the implications of a positive result.

The need for education about Pap smears and cervical cancer is highlighted by the findings presented earlier, of surveys of women conducted by the pilot projects. In the Upper Spencer Gulf survey, 92% of a sample of 258 women agreed with the statement "regular Pap smears could save my life" (Davy et al, 1990 - South Australian pilot project). However, in the Queensland survey, although 96% of the women surveyed knew Pap smears can detect early signs of cancer, 36% of women were unaware that Pap smears are still important once a woman has reached menopause. Women who had not had a Pap smear in the last two years were less likely to be aware of the role of Pap smears.

Fifty-seven per cent of women believed that they were just as likely to get cervical cancer whether or not they had Pap smears, and 39% did not believe that Pap smears help prevent cervical cancer. Women's lack of awareness of the preventive nature of Pap smears was significantly higher for older women and those with low education levels (Cervical cancer screening: A survey of Queensland women - Queensland pilot project).

The significance of these findings is that there appear to be substantial proportions of women who believe that they would not benefit from Pap smears or who believe that the test is only designed to detect established cancer. Fear of the detection of cancer may in itself act as a deterrent to presenting for Pap smears. This highlights the need for the integration of information and education with other activities to encourage attendance. A further implication of the South Australian findings is that education about an appropriate screening interval may result in a reduction in over-screening with the potential for cost savings.

These findings strongly indicate that it is essential for relevant data from research to be used in the planning of education and information resources and campaigns.

The available avenues for education and provision of information include mass media campaigns, community groups and networks, consultations with health professionals, other more personal approaches and a combination of methods.

(i) Mass media campaigns

Data are available from the Queensland pilot project and the New South Wales Cancer Council Cervical Cancer Awareness campaign which demonstrate the efficacy of mass media campaigns in boosting Pap smears.

A campaign conducted in 1989 by the Queensland Cervical Cancer Screening Evaluation Pilot Project, which was aimed particularly at older women, increased the average monthly Pap smear rate by 21% over a three month period. The greatest increase (117%) was found among women over 60 years of age, in whom screening rates had previously been lowest. For women aged 50-59 years, monthly Pap smear rates increased by 39% on average (Queensland pilot project).

A cervical cancer awareness campaign, utilising television, radio and magazine advertising, was conducted by the New South Wales Cancer Council in February 1988. It was primarily aimed at women 50-69 years. Forty per cent of women aged 18-70 years reported awareness of the mass media promotion. Recall was highest for the television commercial. There was a 10% - 20% increase in expected attendance in the four months following the campaign for women in the 20-29 years, 30-39 years and 40-49 years age groups and a 30% increase for women 50-69 years. Increases in Pap smear rates in other States were also observed in this period, but were not as great as that for women in New South Wales aged 50-69 years (Shelley et al, 1989).

The methods used in these projects do not allow examination of the Pap smear histories of women who attended in response to the campaigns. It is therefore not possible to determine the extent to which the increase in Pap smears in women who were previously under-screened or unscreened could be attributed to the campaigns. However, the rate of abnormal Pap smears in the Queensland pilot project increased in proportion to the increased number of Pap smears taken, suggesting that the additional Pap smears may have come from women at high risk. This suggests that such campaigns could substantially improve the effectiveness and cost-effectiveness of cervical cancer screening. However, the duration of the campaign evaluations was not sufficient to examine their long term impact.

(ii) Community groups and networks

Another method of increasing community awareness and knowledge is to use opportunities provided by community and women's groups, clubs and workplaces. Community workers who are members of these groups can be trained as educators to make full use of these opportunities for recruitment. This approach was adopted by the rural project in Western Australia and was one of the strategies used in the Upper Spencer Gulf project in South Australia. Qualitative assessments of these projects suggest that this networking activity has contributed significantly to the success of the projects (Davy et al, 1990; Keenan, 1990). Women attending New South Wales women's health nurses reported that informal community networks were important sources of information about the service. No data are available on the effectiveness of this method of recruitment alone or on its cost-effectiveness.

The four pilot projects which targeted Aboriginal and Islander women in Queensland, and Aboriginal women in the Northern Territory, Western Australia and South Australia, using Aboriginal health workers or Aboriginal community workers as educators, relied extensively on networking in the local communities to educate, inform and recruit women to screening (Davy et al, 1990 - South Australian pilot project; Nolan, 1990 - Northern Territory pilot project; Queensland and Western Australian pilot projects). Aboriginal women in these communities had low screening rates compared with other Australian women and higher rates of abnormal Pap smears.

Data in Table 6.2 show the improvement in screening rates in the Queensland, Northern Territory and South Australian projects from around 10% prior to the projects to 30% and over. As a disproportionate number

TABLE 6.2 Screening rates in pilot projects in Aboriginal communities

Pilot project - target population	Duration of recruitment efforts (months)	Screening rates prior to project (% of eligible women)	Screening rates achieved by project (% of eligible women)
Northern Territory - semi-traditional Aboriginal women in six remote communities	10	10%	Overall: 30%(a) By age: <40 33% (years) ≥40 23%
Queensland - Aboriginal and islander women in six remote communities	5 - 11	13%(b)	Overall: 34%(c) By age: 10-19 22% (years) 20-29 40% 30-39 17% 40-49 12% 50-59 8% 60+ 2%
South Australia - Upper Spencer Gulf. Aboriginal women in one rural community	27	<10%(b)	Overall: 30% By age: 15-19 19% (years) 20-39 37% 40-59 27% 60+ 18%

Notes:

(a) Data based on first 6 months of program.
(b) Estimate.
(c) Rates based on programs of varying durations from 5 to 11 months. Rates varies greatly between communities from 20% to 100%.

of women screened in all projects were under 40 years of age, there are clearly significant impediments to screening older women in Aboriginal communities. In the South Australian pilot project, Aboriginal women were three times less likely to have ever been screened prior to the project. However, two years after the commencement of the project they were participating in screening at equivalent rates to the rest of the community (Davy et al, 1990 - South Australian pilot project). Self reported rates of screening among Aboriginal women in two rural towns in Western Australia were initially 25%.

In the rural and semi-traditional Aboriginal communities participating in these pilot projects, the recruitment activity was found to be especially time and labour intensive. The success of these projects was highly dependent on the interpersonal and communication skills and motivation of the health professionals. Due to the initially low levels of awareness and knowledge of screening, as well as the cultural setting, such personal and intensive intervention appears to be essential to achieve satisfactory screening rates in these high risk women.

In view of the effectiveness of education and recruitment using community groups and networks in selected communities, this method should be considered for use in recruitment campaigns. Due to the time consuming and labour intensive nature of such activity, it may be most appropriately used to boost recruitment among particularly hard to reach groups such as Aboriginal and Islander women and women from non-English speaking backgrounds.

(iii) Other

More direct forms of recruitment, but not personally addressed to any individual women, include reminder messages on Medicare refund cheques and the use of 'letter-box drops' in particular areas. The latter method has been used in the Eastern Goldfields pilot project in Western Australia. However, this strategy was not effective in preliminary trials of recruitment to screening mammography in the Central Sydney Breast X-Ray Program (Irwig and Turnbull, submitted for publication).

(iv) Combined methods

A number of pilot projects used a combination of strategies in their recruitment efforts (see Table 6.3). In the Upper Spencer Gulf region of South Australia, mass media promotions in combination with community and professional awareness activities and the provision of supplementary Pap smear services, resulted in an increase in Pap smears of 60% over a 24 month period (Davy et al, 1990). A similar project in the Australian Capital Territory led to a 32% increase in Pap smears

TABLE 6.3 Screening rates in pilot projects using combined recruitment strategies

Pilot project	Recruitment methods used	Duration of recruitment (months)	Overall increase in screening rates (%)	Increase in screening rates by age groups (%)	
SA - Upper Spencer Gulf	Mass media community education and networks. Professional education. Supplementary services - Pap smear clinics staffed by nurse practitioners.	24	60	Age (years) <30 30-39 40-49 50+	 37 72 65 108
ACT	Media advertisements (television, radio, newspapers, posters pamphlets). Direct promotions and education (within workplaces, social groups and shopping centres e.g. talks and static displays).	12	32(a)	Percentage of women attending ACT clinics aged 40+ years was 65%.(b) Percentage of women in the target population in this age group is 39%.	

(a) Based on figures for Woden Valley Hospital Cytology Department only. Figures from other laboratories in the ACT are not available.

(b) The Australian Capital Territory Pilot Project specifically targeted women over forty years of age.

over a twelve month period. In both projects proportionately greater increases in screening rates occurred among women over 40 years of age, for whom screening rates were initially lowest and at whom the campaigns were targeted. Data to evaluate changes in screening rates are not yet available from the Western Australian and New South Wales screening projects.

A campaign in Newcastle, targeted at women of non-English speaking background using ethnic newspapers and radio as well as education sessions to encourage women to attend Pap smear clinics, found that 45% of women who attended reported never having previously had a Pap smear (Bowman et al, 1990).

As the recruitment methods were combined or used sequentially to boost falling screening rates it is not possible to determine the extent to which individual strategies were effective, or their success if used alone. However, these studies do illustrate that the use of judiciously combined recruitment methods, which simultaneously address several identified barriers to screening, is effective in boosting Pap smears. It is important to note that the multi-faceted campaigns in the Upper Spencer Gulf, South Australia and in the Australian Capital Territory were tailored for specific communities and would need to be adapted for other population groups. Pap smear recruitment campaigns need to be designed and adjusted according to the specific context of their target communities.

3. Individualised invitations to women in the target population

Forgetting to have regular Pap smears was found by the pilot project community surveys to be a significant factor contributing to non-attendance at screening. Forgetting was the most frequently reported reason, given by 31% of women in the Upper Spencer Gulf survey, for not having a Pap smear in the last three years. Sending reminder letters to women due, or overdue, for Pap smears could overcome this problem. Although the pilot projects did not trial personal invitations to women as a primary recruitment method, there is substantial evidence from organised screening programs in other countries that personalised invitations to women to attend cervical cancer screening are effective in recruiting a large proportion of eligible women (see Section 5.2.2).

Strategies which could be used for inviting women for screening include:

(i) Comprehensive invitation, on a regular basis, to individual women in the target population. This involves the sending of a personalised letter of invitation to all women in the relevant age group without reference to the health or Pap smear status of the woman. The letter would need to indicate which categories of women would not need to have a Pap smear, for example those who have had a Pap smear within a recommended interval or those who have had a hysterectomy. The data base for this comprehensive invitation could be either electoral or Medicare records.

(ii) Selective invitation to those who have not had a recent Pap smear. Invitations are sent only to women who have not had a Pap smear within a recommended period. The information base for selection could be either Medicare records of claims for Pap smears or a cervical cytology registry linked to a population register. In terms of public acceptability, selective invitation may be the least acceptable option in the Australian context, as the use of such information may be regarded by some women as an invasion of privacy.

(iii) Recall only. Only women who have previously had a Pap smear are recalled. A significant shortcoming of this strategy is that it misses women who have never had a Pap smear, many of whom are therefore at higher risk of cervical cancer.

There is evidence that both women and medical practitioners consider personalised invitations to women to attend screening acceptable. A survey of 1925 Queensland women by the Queensland Cervical Cancer Screening Evaluation Project in 1989 found that 66% of women thought that invitations from a Statewide reminder system would increase regular screening rates. Seventy six per cent thought that letters from general practitioners would be effective (Queensland pilot project). Of 775 women surveyed in New South Wales, 70-88% said that they would respond to an invitation from a cancer council and 83-99% said they would respond to a reminder letter from their general practitioner. Similarly, 76% of 200 general practitioners surveyed in New South Wales thought that a statewide screening register and recall system to send reminders to women due for Pap smears would increase the number of regular Pap smears (Bowman et al, 1990).

Ninety four per cent of 200 general practitioners surveyed in New South Wales thought that reminder letters to women from their general practitioner would increase the number of women having regular Pap smears. Twenty one per cent of the general practitioners reported having already implemented a Pap smear reminder system and 60% were willing to do so (Bowman et al, 1990).

Databases for individualised invitation

Within Australia there are several possible lists of women on which individualised invitation might be based:

(i) Pathology records from individual laboratories or a cervical cytology registry

Individual pathology labs could use their cytology records as a basis for reminding women who are due for Pap smears. The reporting of Pap smears by many laboratories is likely to make this a difficult process.

The cervical cytology register is a computerised database recording the results of Pap smears and basic identifying information about the woman, the name of her referring doctor and the laboratory where the Pap smear was examined. More detailed information about the functioning of a cervical cytology registry is presented in Section 6.10, but the relevant function in this context is the ability to recall, for a repeat Pap smear, women whose last Pap smear report is recorded in the registry.

(ii) Population registers

There are two possible sources of a population listing in Australia - electoral records and the list compiled by the Health Insurance Commission for Medicare payments.

Electoral records are public documents, although information about age is not publicly available. These listings could be used as a basis for sending out invitation letters by organisations such as Cancer Societies or State/Territory health departments. The acceptability to women of invitations to screening using electoral records was found to be high in the New South Wales Cervical Cancer Screening Evaluation pilot project and in a Victorian project.

The New South Wales Cervical Cancer Screening Evaluation pilot project targeted women aged 18-70 years in two rural communities. Women who were on the electoral register were sent personal invitations by the New South Wales Cancer Council, advising them to have a Pap smear if they had not had one in the past year. Ninety two per cent of women surveyed later said such a letter should be sent to all women and 82% said they would like a reminder sent regularly (New South Wales cervical cancer screening pilot project). In a Victorian study 4000 letters were sent using electoral records. Twelve telephone calls to a toll free number were received from persons who received letters, with only two calls enquiring about the source of the addresses. This suggests a low level of concern among women about the use of electoral records as a method of recruitment. Preliminary analyses indicate that these electoral record based invitations resulted in a substantial increase in screening rate among women over 40 years of age (H. Mitchell, personal communication).

However, there appear to be limitations to the effectiveness of invitations from electoral records in prompting some high risk women to attend screening. This was demonstrated by a trial in Perth in which a comprehensive invitation was sent to all women on the electoral roll in a disadvantaged area of Perth. Most of the women who responded to the invitation were women who had been screened relatively recently (Straton, 1989). Results of the Queensland community survey indicate that older women and women not screened in the last two years would be less likely to respond to recommendations from health authorities or to reminder letters (Queensland pilot project).

Although electoral records are regularly updated, problems may occur with people not being registered or being registered under out of date addresses. Incomplete or inaccurate electoral records could lead to under-representation of under-screened women. In 1986, only 68% of women with cervical cancer diagnosed in 1986 were on electoral records in Queensland (I. Ring, personal communication). A preliminary assessment of the completeness and usefulness of South Australian electoral records for individualised invitations found that the number of women over the age of 18 years on the records was 93% of the number expected from Census data (Davy et al, 1990). Furthermore, 89% of women diagnosed with cervical cancer during 1986-1989 appeared on the records, and 86% of the addresses for these women were correct. However, certain groups at higher risk of cervical cancer were under-represented on the records. Only 77% of women born overseas and 55% of Aboriginal women were on the records in South Australia, and only 40% of Aboriginal women had an accurate address recorded. There was only minor variation in likelihood of being on the electoral records in relation to socioeconomic status.

The Medicare list is more frequently updated than electoral records and is more comprehensive, although it apparently contains some duplication. If the Medicare list were to be used, the Health Insurance Commission may have to be responsible for the production of the invitations. Current privacy laws preclude the names and addresses of people listed with Medicare being available to outside organisations for public health initiatives. This issue must be addressed by governments as a high priority.

(iii) General practitioner patient lists

These are lists compiled from the patient records of general practitioners. In Australia such lists would have a number of potential limitations: women may attend several general practitioners and would thus appear on more than one list; compiling the initial lists would be very laborious; updating the lists would be difficult in the event of a woman ceasing to attend a particular general practitioner; and some women may rarely or never attend a general practitioner.

Some general practices have computerised patient registers which could be used for personalised invitations. However, a State/Territory wide register could be complementary to these practice-based registers and could pick up women who are not being reminded by a general practitioner.

In Western Australia, invitations from the cervical cytology registry are being designed so that, as a first step, the practitioner who took the previous Pap smear will be sent a list of those women who are due for a repeat Pap smear. Women who do not respond to initiatives through the medical practitioner will be sent a letter directly.

The effectiveness of reminders issued by general practitioners was shown by previous Australian research which found that 32% to 37% of unscreened women had a Pap smear in response to a letter from their general practitioner (Pierce et al, 1989; Bowman et al, 1990).

The acceptability to women of reminder letters from general practitioner lists was tested in the Upper Spencer Gulf project in South Australia. Of a sample of women attending a special screening clinic, 87% agreed to be enrolled in a voluntary reminder system (Davy et al, 1990). However, only 20% of a sample of 1303 women who attended private general practitioners agreed to participate. This much lower compliance rate is likely to be due to the reminder service not being promoted so actively by the general practices involved.

Choice of strategy

If individualised recruitment is to be used, different strategies may be appropriate at different stages of development of the program. For example, in the early stages of an organised approach it would probably be more appropriate to use a combination of methods for promoting cervical cancer screening until there is a substantial majority of women on general practitioner or laboratory registers and on a back-up cervical cytology registry. After this the registry could be used as the main basis for individualised reminders, combined with other methods of recruitment. Alternatively, reminder letters based on the registry to previously screened women could be combined with a comprehensive invitation to particular age groups known to be poorly screened.

6.3.3 Conclusions

The results of the pilot projects and other research have identified several strategies which are effective in increasing participation of women in cervical cancer screening. Mass media campaigns have been found to be effective at least for the comparatively brief durations for which they have been evaluated. Additional interventions such as general practitioner initiation of screening, supplementary services and reminder letters will be required to maintain higher screening rates.

Significant increases in screening are possible with increased initiation of screening by general practitioners. Professional education to maximise this strategy is required.

At the present time, using personalised letters inviting women to be screened appears to be most appropriate as a safety net for those women who are not otherwise prompted to attend screening. This method has been found to be very effective in other countries and pilot project data indicate favourable attitudes of Australian women to this method of recruitment.

A community approach to encourage women to be screened was found to be essential in Aboriginal communities and may also be necessary for women of non-English speaking background.

The provision of supplementary services is also an important issue in recruitment. This is discussed in the next section.

Thus, a number of different methods of recruitment can be effective. The optimal combination of strategies needs to be tailored to each community. This should be determined locally. An important component of this tailoring of strategies is the need for ongoing monitoring and evaluation of the effectiveness of the strategies implemented.

6.4 COLLECTION OF THE PAP SMEAR

The success of any cervical cancer screening program will depend on the provision of high quality services which are both acceptable and accessible to women. Ideally, there should be a range of Pap smear-takers (doctors and nurses) at a range of locations (general practice, family planning, other "well women clinics" and hospitals), so that women have a choice of service providers.

Provision of Pap smear taking services

(i) General practice

As discussed in Section 6.3.2 most Pap smears are currently taken in Australia by general practitioners and it is likely that this will continue to be the case as they are seen by the majority of women as appropriate and acceptable providers of Pap smear services. The general practitioner is a key person in any cervical cancer screening program, and measures must be taken to maintain the active involvement of general practitioners in the State/Territory programs.

It is necessary to explore ways of making the service provided by general practitioners more accessible and acceptable to women. Organisation of cervical cancer screening sessions within the practice may provide a framework which may be more efficient and could help to overcome the reluctance of some women to ask for Pap smears and of some doctors to offer them.

(ii) Supplementary services

Although it is likely that the majority of Pap smears will continue to be taken by general practitioners, there is a need for women to have a choice. Some women do not have a regular general practitioner, or would prefer to have their Pap smear taken by someone else. Many women prefer to have their Pap smear taken by a female practitioner. Community surveys conducted by pilot projects in New South Wales and Queensland found that 36-53% of women preferred their Pap smear to be taken by a female practitioner, while around 50% of women expressed no preference (See Table 6.1). Preference for a female practitioner is stronger among women who attend nurse practitioner services: seventy per cent of all women attending Australian Capital Territory pilot project Pap smear clinics preferred a female practitioner and 64% of New South Wales women's health nurse clients thought it was very important to have a female Pap smear taker. Women were more concerned about the gender of the practitioner than whether the practitioner was a doctor or nurse. A New South Wales survey of 200 general practitioners found that general practitioners themselves recognise the need for alternative cervical cancer screening services (Bowman et al, 1990). Fifty two per cent of 31 male general practitioners surveyed in the Western Australian pilot project thought that more women would have Pap smears if female practitioners were available.

The availability of female general practitioners has increased as more women have entered general practice: it remains a significant problem in some rural areas. Data from the Queensland pilot project statewide survey of 1925 women and the Western Australian survey of 402 rural women suggest that the unavailability of female doctors inhibits a small but significant number of women from being screened. Eleven per cent of the Queensland women reported that the absence of a female doctor in their town acted as a deterrent to their participation in screening and 65% thought more Pap smears would be taken if there were more female doctors. Seven per cent of the 29 Western Australian women who had never been screened reported that the lack of a female practitioner deterred them from being screened.

Women seeking an alternative service are served by existing organisations such as the Family Planning Association, but this is less appropriate for older women with no further need for contraception.

Pilot projects in the Australian Capital Territory, Queensland and South Australia tested the effectiveness and acceptability to women of special Pap smear clinics staffed by either nurse practitioners trained in taking Pap smears (Australian Capital Territory and South Australia) or female doctors (Queensland). The New South Wales Women's Health Nurse evaluation project assessed the provision of Pap smears by nurses with training in Women's Health, who as solo practitioners provided comprehensive services in women's health clinics. It was found that women who attended the screening or women's health clinics tended to be from under-screened or unscreened groups (See Table 6.4).

Data from the Upper Spencer Gulf pilot project show that, in comparison with the women who attended a general practitioner for screening, the women who attended a special screening clinic and a community health centre (mostly Aboriginal women) for screening were substantially more likely to report never having been screened before or having not been screened for over four years. Older women were more likely to attend the special screening clinic staffed by a nurse practitioner rather than their usual general practitioner, while Aboriginal women were much more likely to attend the Community Health Centre, which was their usual health service and had a female doctor. This experience suggests that it is the availability of a female Pap smear taker rather than the location of the clinic which is the more important factor influencing women's attendance at screening clinics.

Of women who attended Pap smear clinics staffed by a female doctor in the Queensland rural pilot project, 53% reported not having a Pap smear in the last two years compared with 32% of women in the statewide survey. Thirty nine per cent of Australian Capital Territory clinic attenders and 46% of women's health nurse clients in rural areas reported they had not had a Pap smear for over three years.

TABLE 6.4 **Percentage of women attending screening services from specific risk groups compared with the target population(a)**

	Never screened before or not screened for over 2-5 yrs (Qld) 3 yrs (ACT, SA & NSW)(b)	Women aged 40+y (Qld, ACT & NSW) or 50+y (SA)	Aboriginal women(e)
SA			
Women attending for screening at:			
- **Supplementary screening service**			
Special screening clinic (n=739)	46	33	6
Hospital screening clinic (n=67)	23	18	3
- **Usual health care**			
Private GP (n=2508)	35	17	3
Community health centre (Aboriginal) (n=301)	46	12	57
Target population:			
Whyalla, Port Augusts and Port Pirie (n=16464)	-	49	8
ACT			
Women attending for screening at:			
- **Supplementary screening service**			
Special screening clinics (n=434)	39	65	-
- **Usual health care**			
GPs and community health centres (n=9165)	-	26	-
Target population:			
All of Australian Capital Territory (n=103132)	-	39	-
QLD			
Women attending for screening at:			
- **Supplementary screening services**			
Special screening clinics (n=341)	53	47	-
- **Usual health care**	-	-	-
Target population:			
Ten rural towns (n=11004)	32(c)	33	-
NSW			
Women attending for screening at:			
- **Supplementary screening service**			
Women's health nurse clinics (Sydney, n=439)	46	73	-
(rural areas, n=964)	27	45	-
(overall, n=1403)	-	47	-
- **Usual health care(d)**	-	33	-
Target population:			
All of NSW (n=965038)	-	46	-

Notes:

(a) Screening rates not adjusted for hysterectomy status.
(b) Based on self-reported screening history.
(c) Figure based on survey of entire State.
(d) Based on a 10% sample of New South Wales Health Insurance Commission Pap smear claims in 1987.
(e) Based on Port Augusta only.

Older women were targeted in both the Australian Capital Territory and Queensland rural pilot projects and preferentially attended the Pap smear clinics; 70% of women who attended Australian Capital Territory Pap smear clinics were over 40 years of age, compared with 26% of women screened by general practitioners; 48% of women attending Pap smear clinics in the Queensland rural project were over 40 years compared with 33% of all women in the region who had Pap smears. Forty seven per cent of women attending Women's Health Nurses were over 40 years, compared with 33% having Pap smears with general practitioners.

A screening program in rural Victoria, which consisted of a community based campaign and special screening clinics, increased the number of Pap smears taken by 50% during the month of the campaign. Older women and women who had not been screened previously preferentially attended the screening clinics. Seventy per cent of women screened in the clinics were 40 years of age or above compared with 36% of women being screened by general practitioners; 52% of women screened in the clinics had not had a previous Pap smear compared with 29% of women screened by general practitioners (Hirst et al 1990).

These data show that women who attend supplementary Pap smear services are more likely to be at higher risk from cervical cancer due to being older, having infrequent Pap smears or never having had a Pap smear. Thus these services can play a crucial role in increasing Pap smear rates among the highest priority group: under-screened women.

Women attending nurse practitioners were very satisfied with the service provided and found nurse practitioners acceptable Pap smear takers. Ninety five per cent of women in the New South Wales Women's Health Nurses study reported that they were "very satisfied" with the services provided. Of 53 women surveyed in the Australian Capital Territory clinics a high degree of satisfaction with service was expressed by 89% of respondents.

Data on the adequacy of Pap smears taken by nurse practitioners in the New South Wales Women's Health Nurse evaluation project and the Australian Capital Territory and Northern Territory pilot projects show that nurses can be trained to a high standard for taking Pap smears. In all three projects, trained nurses obtained satisfactory Pap smears at rates at least equivalent to medical practitioners (see Table 6.5).

Under present arrangements, to receive Medicare funding Pap smear clinics and other supplementary services are not legally permitted to advertise their services. This reduces their effectiveness in recruiting women to screening and is an issue which needs to be resolved at the Commonwealth level. If States/Territories were to receive a funding allocation from the Commonwealth for recruitment, some of this money could be used to fund screening clinics outside the Medicare payment system.

TABLE 6.5 Adequacy of Pap smears taken by practitioners(a)

Pilot project	Practitioner taking Pap smear	No. of Pap smears taken	Percentage of Pap smears which are adequate
NSW women's health nurses evaluation	Nurse practitioners	2,020	97
	All other practitioners using same laboratory	73,689	91
Northern Territory Traditional Aboriginal women	Community Health Nurse	168	86
	District Medical Officer	107	87
ACT	Nurse practitioners	434	97
	All other practitioners using same laboratory	9,599	86
Western Australia(b) – rural towns	Nurse practitioners	234	79
	General practitioners	920	78

Notes:

(a) Adequate Pap smears are defined as those which are technically satisfactory and contain an endocervical component.

(b) Preliminary data for January–June 1990.

(iii) Hospitals

One possibility for encouraging the participation of previously unscreened women is to make use of opportunities provided by their contact with the health care system for other reasons. Within hospitals, Pap smears could be taken by specially trained nurses or by hospital resident doctors. However, the heavy workloads of resident doctors would in many cases preclude their taking Pap smears.

Overseas studies have demonstrated the effectiveness of nurse practitioners in taking Pap smears on hospital inpatients (Hudson et al 1987).

Comment

There is currently an adequate number of general practitioners for taking Pap smears. However, some States and Territories have particular problems with providing acceptable services to rural women, Aboriginal women, women of non-English speaking background and women who prefer female Pap smear takers.

The pilot projects have demonstrated the effectiveness of supplementary services such as Pap smear clinics or women's health nurses in increasing women's attendance at screening, particularly those at higher risk of cervical cancer due to their age or to the infrequency of previous Pap smears. Each State and Territory should develop the supplementary services it requires for the taking of Pap smears.

Ensuring the quality of Pap smears

A Pap smear can predict abnormalities of the cervix only if cells are collected from the area of abnormality. Given the range of anatomical variation of the cervix, it is appropriate that laboratories supply practitioners with a variety of sampling instruments.

There is general agreement on what constitutes an unsatisfactory Pap smear (e.g. poor cellularity or fixation, excessive blood staining or cytolysis). There is debate concerning adequacy of the specimen. While a number of studies have indicated a higher prevalence of abnormality in Pap smears which include an endocervical component (Laverty et al, 1989; Mauney et al, 1989; Vooijs et al, 1985), longitudinal studies of women whose Pap smears lack endocervical cells have not demonstrated a higher rate of abnormality in the later Pap smears (Kivlahan and Ingram, 1985; Vooijs et al, 1984). There is concern that Pap smears lacking endocervical cells are sub-optimal. There is no consensus on how soon such Pap smears should be repeated.

Practitioners should be able to receive periodic statistics from the laboratory which reports their Pap smears on the basis of the proportion of Pap smears which are unsatisfactory for diagnosis and the proportion of Pap smears which lack an endocervical component. The profile across all practitioners who use the laboratory could be provided for comparison. Experience of laboratories providing this information is that it has been well received by clinicians. For such feedback to be effective, it is important that comprehensive educational materials and courses for improving the quality of Pap smears be available for practitioners who are concerned about the quality of their Pap smears.

6.5 REPORTING PAP SMEARS AND NOTIFYING RESULTS

Pap smear reporting

The task in reporting Pap smears is to identify those specimens which contain abnormal cells which, in the absence of treatment, would have a high probability of progression to invasive cancer. Examining Pap smears is labour intensive. Each slide, comprising several hundred thousand cells, must be carefully and systematically scrutinised.

Current shortcomings

In Australia there are currently a number of shortcomings in the process of Pap smear reporting:

- There is lack of standardisation of reporting abnormal Pap smears, particularly in relation to 'minor' abnormalities (Armstrong et al, 1986).

- There is lack of agreement in the recommendations for management of cytological abnormality.

- There is no systematic feedback to practitioners about the quality of the Pap smears they take.

- There are no minimum education standards for cytotechnologists.

- The accuracy of reporting within laboratories is unknown.

Laboratory accreditation and registration

Since 1986, laboratories have been required to apply to the Commonwealth Department of Community Services and Health for "provisional" accreditation if they are to be eligible for Medicare payments from the Health Insurance Commission. Following provisional accreditation, laboratories must apply for registration by the National Association of Testing Authorities (NATA) and the Royal College of Pathologists of Australasia (RCPA). NATA/RCPA registration is only granted after successful assessment according to criteria set by the National Pathology Accreditation Advisory Council (NPAAC). NPAAC is currently revising its present pathology laboratory standards. Laboratories which have been registered are to be reassessed every two years.

By April 1990, half of the laboratories which had applied for NATA/RCPA registration had achieved registration. Of the remaining laboratories, half had been visited in either an assessment or advisory capacity. Approximately 150 laboratories distributed around Australia had still to be visited. It is unclear how many of these laboratories undertake cytology.

During the initial phases of assessment of cytology laboratories, a number of difficulties were apparent. This has resulted in laboratories being required to conform to the following policies to be eligible for registration:

- The use of off-site, free-lance cytotechnologists is not permitted.
- Supervising pathologists must have formal training or experience in cytology or the pathologist must be undergoing training in cytology and have formal consulting arrangements with a specialist cytopathologist.
- Formal procedures must be in place to follow up women found to have abnormal Pap smears, both for the woman's benefit and as an internal quality control procedure.
- Laboratories must participate in external quality assurance programs where available.

A major concern is that there is no assessment of the accuracy of day-to-day work. Lack of information on the accuracy of day-to-day reporting contributes to practitioners advising frequent rescreening.

Since 1986, the Royal College of Pathologists of Australasia has conducted external quality assurance programs which assess the accuracy of interpretation using test slides. In 1987, a pilot study of this program involving 30 laboratories recorded a five per cent incidence of substantial deviation from panel opinion. In 1988, the slide rotation component showed that 22% of the participating laboratories (n=168) had a substantial deviation or major error in the interpretation of the slides. In 1989, 26% (n=169) showed a deviation from the panel opinion. While useful, this program provides no information on the accuracy of day-to-day reporting.

A second concern is that there is no acceptable qualification for cytotechnologists. Rather, assessment is based on experience and qualifications which may include a Cytotechnologist Australian Society of Cytology qualification. Formal training in cytotechnology is being encouraged using a course conducted by Colleges of Advanced Education.

Internal quality assurance procedures

A range of procedures can be used by individual laboratories to improve and maintain the quality of test reporting:

- hierarchical organisation structure
- staff training and continuing education
- rescreening samples of slides
- frequency analysis of reports for each Pap smear reader
- reviewing previous Pap smears where there has been a worsening of diagnosis between two successive Pap smears or where cervical cancer is suspected

- correlating cytology with anatomical pathology
- reviewing Pap smears of cervical cancer cases

The proportion of cytology laboratories which perform these internal quality assurance measures was examined in a survey of laboratories conducted by the Screening Evaluation Coordination Unit of the Australian Institute of Health. Self-report questionnaires were mailed to all registered pathology labs (approximately 700). One hundred and six responses were received from the approximately 180 laboratories which undertake cytology, giving a response rate of approximately 60%. The proportions of cytology laboratories which responded to the survey and use the various quality assurance measures described above are shown in Table 6.6.

TABLE 6.6 Proportion of cytology laboratories which use various internal quality assurance measures

Quality assurance measure	Proportion of laboratories(a)
Hierarchical organisational structure	66%
Staff training and continuing education	
• staff meetings	66%
• in-house training	46%
• demonstration slides	62%
• other	87%
Rescreening samples of slides (negative reports only)	38%
Frequency analysis of reporting codes	15%
Reviewing previous Pap smears when serious abnormality found	attempted by 96%
Correlating cytology with anatomical pathology	attempted by 92%
Reviewing Pap smears of cervical cancer cases	attempted by 27%

Note:

(a) Proportion of the approximately 60% of laboratories which responded to the questionnaire

Source: Screening Evaluation Coordination Unit, Australian Institute of Health

In addition to the quality assurance measures listed in Table 6.6, 26% of laboratories reported they monitored the proportion of cases where the cytology failed to predict a serious lesion which was later diagnosed by histology (i.e., the false negative rate).

When asked to show how they calculated the false negative rate, most laboratories indicated an understanding of the method of calculating false negative rate, although only 14% presented an accurate method of calculation. A number of laboratories indicated they were severely hampered in trying to monitor their false negative rate as records of a women's previous Pap smears or later histology were rarely accessible by them in any comprehensive fashion.

These data indicate that a number of important quality control measures are utilised by only a small proportion of laboratories. Furthermore, the picture presented in Table 6.6 may be an optimistic assessment of the level of internal quality assurance activities, it being likely that laboratories which undertake such measures would tend more to have responded to the questionnaire.

While the most common quality assurance measure attempted by laboratories was a review of previous Pap smears when a serious abnormality was found, it is probable that even this measure is vastly under-used given the dispersal of Pap smear reporting into many laboratories. Many laboratories simply do not know the identity of cases for whom they have issued a negative report but who have had an abnormality reported soon afterwards by another laboratory.

For a number of these quality control measures to be implemented, it is necessary for Pap smears to be retained for considerable periods of time. Currently, under NATA/RCPA laboratory accreditation requirements, cytology reports and slides which show evidence of malignancy or possible malignancy should be kept for fourteen years. Other reports and slides should be kept for two years. The National Pathology Accreditation Advisory Council (NPAAC) is currently reviewing its guidelines on slide retention. NPAAC guidelines are adopted by NATA/RACPA for laboratory accreditation. Only Victoria has legislation enforcing slide retention for the time stipulated by NPAAC.

Summary

The National Cervical Cytology Screening Advisory Committee should make recommendations to the National Pathology Accreditation Advisory Council, the National Association of Testing Authorities and the Royal College of Pathologists of Australasia on the minimum accuracy standards which are appropriate for laboratory accreditation. Emphasis should be the accuracy of day-to-day work rather than on laboratory processes. The recommended rescreening interval of two years will only be accepted by clinicians and women if there is adequate documentation of the accuracy of day-to-day work.

Within three years only laboratories which meet these minimum standards should receive public funding for reporting Pap smears.

An annual report of the accuracy of reporting should be compiled at a State/Territory level and should be consolidated at a national level. Every accredited laboratory should provide at least an annual report on the quality of their Pap smears to individual practitioners.

Notification of results

Current practice for the notification of results is for the cytology laboratory to provide the result to the woman's practitioner, who then provides the result to the woman. A significant problem is the practice of advising women that they will be notified of the result only if the test is positive. If women are only expecting a notification if the test is positive, they may interpret failure to receive a result as being due to a clear test when in fact an abnormal result may have been mislaid. At the other extreme, some women are asked to return to their general practitioner to receive a normal result. This may result in unnecessary inconvenience to the woman and unnecessary expense.

At the time of Pap smear taking all women should be advised by the Pap smear taker that they will be notified of the test result, irrespective of whether it is positive or negative. They should be advised that if they have not received a result after a specified interval, they should inquire of the person taking the test.

In cases with positive Pap smears, a survey in Western Australia (Robbins et al, 1986) indicated that most general practitioners personally notified women with abnormal Pap smears by phone. This form of direct notification may be a more acceptable procedure for abnormal Pap smears, as explanation and information to allay anxiety can be given immediately with the result.

Notification of all results directly to women by laboratories or registries is contentious. If women were to be notified of results directly by a laboratory or registry, anxiety and misinterpretation of a positive result may occur.

6.6 FOLLOW-UP OF WOMEN WITH ABNORMALITIES

Once a Pap smear has been diagnosed as showing a significant abnormality, it is necessary for the woman to receive appropriate medical care. Currently there is no organised mechanism for ensuring that this occurs. This results in some women not getting necessary treatment (for example, 10% of women with cervical cancer in Queensland have a previous abnormality which was not treated, while in Victoria 13% of women with cervical cancer either had an abnormality which was treated and then recurred or had an abnormality which was not treated on the first occasion (Mitchell, 1990).

If the current two stage notification of results procedure (laboratory -> practitioner -> woman) is maintained, it is important that a safety net is in place to ensure that women with important abnormalities are not overlooked. This safety net function can be performed by either laboratories or registers.

6.7 SERVICES FOR MANAGING WOMEN WITH ABNORMAL PAP SMEARS

Up to 15% of women are found to have abnormalities on their Pap smears. Approximately half of these result in treatment of an infection or repeat Pap smears to monitor minor abnormalities. Less than two per cent of tests report definite evidence of CIN or invasive cancer which require further assessment including colposcopy. In Australia, colposcopy is practised widely by private gynaecologists and in hospital outpatient departments. A small number of general practitioners also perform colposcopy.

There are several problems with current management services. The lack of Australian data on which to base management has been highlighted in Section 5.4.2. Other problems are the lack of a system for follow-up of women who have been treated to ensure they are rescreened (some abnormalities recur), the lack of monitoring to ensure that treatment is effective and the lack of access to management services for some women in remote areas.

The indications which clinicians in Australia use to decide whether colposcopy is necessary and which forms of treatment should be used vary. In part, this is unavoidable due to the unique characteristics, circumstances and wishes of each woman with a cervical abnormality, making the rigid application of protocols problematic. Another factor may be the variation in the management recommendations of laboratories (discussed above in Section 6.5) and variation in the guidelines produced by professional societies and in those used by individual colposcopists. Nevertheless, there is a role for standardised management guidelines which suggest preferred practice.

To improve this situation, examination of all currently available data for the outcome of minor abnormalities should be undertaken in order to develop management guidelines. It is recognised that moving towards nationally agreed guidelines would require the overcoming of some obstacles. It is likely that this would best be achieved by a program of discussion, research and data dissemination undertaken by the relevant professional societies and colleges, possibly sponsored by a national cervical cancer screening coordination body.

6.8 PROFESSIONAL EDUCATION ABOUT CERVICAL CANCER SCREENING

The proposed strategy for improving cervical cancer screening acknowledges that some States and Territories may wish to use specially trained nurses as well as doctors for the taking of Pap smears. Issues of professional education therefore include the education of nurse practitioners in addition to medical practitioners.

Education of general practitioners should occur at both undergraduate and post-graduate level. Post-graduate education should comprise education during intern and residency training, training in the Family Medicine Program and participation in continuing education.

Guidelines about the cervical cancer screening program, including management of various abnormalities, should be published and distributed to all practising doctors, with regular updates in the light of scientific evidence. Discussion forums with gynaecologists, epidemiologists and cytologists are also important.

National medical publications received by many doctors provide an important setting for discussing issues and for keeping medical practitioners informed of the various recommendations. Bodies such as the Australian Medical Association and the Royal Australian College of General Practitioners have an important role to play, and their cooperation should be sought.

Opportunities should also be provided for general practitioners to improve their skills at taking Pap smears. A program of this nature is currently being provided at Westmead Hospital. A pilot project in the Hunter Valley is studying the impact of a skills development program for general practitioners. More use could be made of training videos.

Nurse practitioner training

Comprehensive programs for nurse practitioner training are currently offered by various family planning associations, the courses being accredited by the Family Planning Federation of Australia. In New South Wales, there is a program for women's health nurses, conducted jointly by the Family Planning Association and the College of Nursing.

In training nurses for a cervical cancer screening program, it is important to be clear about the roles for such nurses, that is whether they will be 'Pap smear taking nurses' or more broadly educated women's health nurses. Experience in New South Wales and the Upper Spencer Gulf pilot project suggests that the issues which women want to discuss with nurses working in this field are broader than cervical cancer screening alone. Although in many instances, the nurses' role is likely to involve appropriate referral, it is important that they be broadly educated in women's health.

6.9 MONITORING AND EVALUATION

The performance of cervical cancer screening, laboratory and treatment services should be monitored in a standardised way by the routine ongoing collection and analysis of data. This is essential because only in this way can governments, service providers and women be confident that the expense and the potential discomfort and anxiety of the program are justified in terms of its success.

Furthermore, monitoring data provides an important management tool for improving the quality of the service. Apart from the pilot projects, monitoring and evaluation of cervical cancer screening in Australia is grossly inadequate. Cytology registers are strongly recommended as a means of providing information to make comprehensive monitoring and evaluation possible.

Performance should be measured in terms of:

- epidemiologic and service delivery parameters
- cost
- acceptability to women

Infrastructure requirements

National standards for classifying and coding screening data are essential so that results can legitimately be compared. This coordination should be undertaken by a national Secretariat (see Section 8.3). Within each State/Territory, responsibility for the data collection and analysis needs to be defined (see Section 8.4).

The provision by cytology laboratories of data for the purpose of monitoring should be a requirement for accreditation to participate in cervical cancer screening.

Data sources

Data will need to be collected in two contexts:

- routine data collection to monitor the ongoing performance and outcomes of programs
- data collection tailored to the evaluation of specific initiatives aimed at improving particular aspects of the service.

The data required for monitoring a screening program can come from a variety of sources, including:

- sample surveys of women in the population and of women who attend for screening (e.g. acceptability to women, reasons for non-attendance, coverage of screening)

- routine data collection by cytology laboratories (e.g. abnormality rates, quality of Pap smears)

- review of Pap smears of women diagnosed with cervical cancer

- routine data collection by a cytology registry

- routine data collection by Health Insurance Commission (e.g. cost, over-screening).

For most areas of screening performance, several sources can be used, although some will provide more comprehensive information than others. Judgement will need to be made as to the adequacy of performance measures based on partial data. For example, analysing data from individual pathology laboratories which do not have monopolies to determine whether women are being screened more frequently than recommended will probably underestimate the extent of over-screening.

The data sources to be used to monitor and evaluate each area of screening performance should be at the discretion of the States/Territories in consultation with the national secretariat. Table 6.7 identifies potential data sources for monitoring each area.

Compilation and dissemination of statistics

The system of collecting data and the analysis to derive performance statistics should be decentralised in order to maximise the impact of monitoring on the quality of services. The State/Territory units should be responsible for compiling statistics at the local level and the recommended national secretariat should be responsible for compiling a national profile.

The National Cervical Cancer Screening Advisory Committee recommended in this Report should determine the information requirements for national monitoring.

At a minimum, the following data should be collated annually:

- age specific screening rates

- rates of abnormality on screening tests

- accuracy of the tests reports (endocervical rate, interval cancer rate, positive predictive value of a report of CIN or worse)

- screening histories of women with cervical cancer.

Monitoring of the long-term outcome of treatment for screen-detected abnormalities and the cost of the screening

TABLE 6.7 Potential data sources for monitoring screening performance

Focus area of monitoring	Potential data sources	Adequacy
Participation	Sample surveys of women	Sub-optimal
	General practice lists	Sub-optimal
	Cytology registry + Census	Optimal
	Health Insurance Commission + labs + Census	Sub-optimal
	Review of Pap smears	Sub-optimal
	Screening histories of women with cervical cancer	Sub-optimal
Adequacy of Pap smears	Labs	Optimal
Overscreening	Labs	Sub-optimal
	HIC	Sub-optimal
	Cytology registry	Optimal
	Sample surveys of women	Sub-optimal
Predictive value positive	Labs	Optimal if comprehensive histological data available
	Cytology registry	Optimal
Fail safe	Cytology registry	Optimal
	Labs	Sub-optimal
	General practice lists	Sub-optimal
Interval cancers	Cancer registry + cytology registry	Optimal
Screening histories of women with cancer	Labs + cytology registry	Optimal
	Labs	Sub-optimal
Disease patterns	Cytology, cancer and death registries	Optimal
Cost	HIC data	Sub-optimal
	Surveys of women screened	Optimal
	Surveys of service providers	Optimal
Acceptability to women	Sample surveys of population, attenders and non-attenders	Optimal

program should be ongoing, but not necessarily annual. Evaluation of women's satisfaction and of recruitment campaigns should be at the discretion of the States and Territories.

6.10 CYTOLOGY REGISTRIES

Potential functions of cytology registries

A cervical cytology register is a computerised data base of the results of Pap smears, together with basic identifying data about the woman and her referring doctor. Registries of women having Pap smears were recommended as far back as the 1976 Walton report (Walton, 1976). The need for registries was emphasised in the 1988 Cartwright report in New Zealand (The Report of the Cervical Cancer Enquiry, 1988).

A cervical cytology registry performs two main functions: a service function and an epidemiological function. In detail these are as follows:

Service functions

Facilitating attendance by women at appropriate screening and treatment:

- Back up recruitment system, with invitation to women for routine rescreening using individualised reminder letters (see Section 6.3.1).
- Providing a fail-safe system to ensure follow-up of women with significantly abnormal Pap smears by generating letters to doctors if a repeat Pap smear or histology report is not received by the registry within a certain period.
- Recording individual women's cervical cytology histories to aid in management, with this information available to clinicians and pathologists. Where there are multiple cytology laboratories with overlapping catchment areas, this function can only be performed practicably by a cytology registry.

Providing quality control mechanisms for screening:

- Documenting the quality of Pap smears.
- Providing histology and cytology reports to pathologists for cyto-histo correlation and for correlation between different Pap smears from the same woman.

Epidemiological/monitoring functions

- Monitoring participation rates by women in the target age group.
- Evaluating the response of women to campaigns to increase screening rates.
- Documenting the accuracy of negative reports by linkage with a cancer registry.

- Determining the prevalence of cytological abnormality.
- Monitoring the response rate to reminder letters which are sent to practitioners and women.
- Monitoring the effectiveness of surgical intervention for women with abnormalities.

As indicated above, a number of these functions can be performed without a cytology registry. However, a cytology registry has the potential not only to fulfil the above functions efficiently but also to provide an essential infrastructure for cervical cancer screening.

Establishing a cytology registry

The essence of a cytology registry is the provision of Pap smear data by participating pathology laboratories. Other desirable data include histological data from cervical biopsies and data from cancer registries and death registries on cases of and deaths from cervical cancer.

Key issues to be considered when establishing a registry include the following:

- A high level of participation by laboratories is essential if the registry is to perform its functions. This can be facilitated by:
    - providing laboratories with legislative protection against legal action for provision of data
    - providing laboratories with a useful service e.g. readily available cervical cytology histories for individual women
    - minimising the expense and inconvenience to laboratories from participation in the registry.
- It is essential that concerns about the confidentiality and security of the information held be addressed.
- The level of resourcing must be sufficient for the registry to function effectively.
- The registry must be responsive to community and professional needs and concerns, and must demonstrate its usefulness to cervical cancer screening.
- The registry must be cost-effective.

A Statewide Victorian Cervical Cytology Registry commenced full operation in November 1989 after a two month pilot period. Establishing the Victorian Registry required an amendment to the Cancer (Central Registers) Act to allow pathology laboratories to pass information to the Registry without the signed consent of each woman. The amendment was passed with the support of all political parties. In

Victoria, the rights of the woman are preserved in that each person who takes a Pap smear is required by the legislation to inform the woman about the Registry. In the absence of a protest being lodged, all test results from participating laboratories are sent to the Registry. At the date of presenting this report, no pathology laboratory had refused to participate in the Registry and the refusal rate among screened women was estimated to be one to two per cent.

Participating laboratories can transmit the relevant details to the Victorian Registry via hard copy or facsimile. With facsimile, the Registry is able to provide the laboratory with a woman's known screening history within one hour. (This occurs during the time the slide is being stained and coverslipped.) The current slide can then be reported in the light of the past history. After the report on the slide has been made, a summary numeric code of the result is passed back to the Registry to add to the woman's history. This process does not change the usual two stage notification system (laboratory -> practitioner -> woman).

Protocols for Registry reminder and follow-up functions have been developed in conjunction with relevant parties. Where the Pap smear was negative, a reminder letter is to be sent from the Registry to the woman at 36 or 18 months (depending on whether the last Pap smear had or did not have an endocervical component) if no further Pap smear has been lodged for the woman at the Registry by this time.

All follow-up for women with abnormal Pap smears is transacted in the first instance either through the laboratory or the last practitioner. For example, where the last report was of minor non-specific changes, the repeat Pap smear reminder is sent to the last practitioner. If no action is forthcoming after three months, a reminder for another Pap smear is sent to the woman. The follow-up of women with more significant abnormalities such as CIN proceeds first via the laboratory, then via the practitioner and, only if the two preceding measures have failed, by means of the Registry writing directly to the woman.

The Registry facilitates the interchange of relevant histopathology results between laboratories.

The Registry will be able to determine the statewide picture of cervical cancer screening in Victoria. Specifically it can determine the number of Pap smears which are taken and the number of women who are screened, the participation of women according to age, area of the State and socioeconomic status, abnormality rates, accuracy rates (including positive predictive value and interval cancer rate), outcome status for women who receive management following abnormal Pap smears, natural history studies, and the screening histories of women who develop invasive cancer. In summary, it provides a very significant infrastructure for an organised approach to cervical cancer screening in Victoria.

Western Australia has undertaken planning for implementation of a Statewide cytology Registry. The Registry has been operating on a trial basis in the South Eastern Statistical Division, a rural area of Western Australia. The two pathology laboratories currently contributing to the Registry have computer systems compatible with the Registry computer. This allows cervical cytology data to be transferred to the Registry on floppy discs. At present, aggregated data are used for monitoring purposes only.

Changes to the regulations of the Health Act covering the privacy considerations required to facilitate the operation of the Registry are being drafted. A Working Party has been established to provide information about the Registry and its proposed functions to community and professional groups. Wide consultation and cooperation with these groups is necessary to foster their understanding and support for a registry.

It is intended that the Registry function in a similar way to the Victorian Cervical Cytology Registry. When the Registry is fully operational it will monitor follow-up of women with abnormal Pap smears requiring investigation and provide written advice to the woman's general practitioner when investigation is not completed within an appropriate interval. The Registry will also recall women with previous normal Pap smears who are overdue, for a routine Pap smear. The exact nature of the recall system is to be determined by the Working Party.

More complete reports on the Victorian and Western Australian Registries are presented in Volume 2. The financial costs involved in setting-up and operating these Registries are outlined in Section 7.1.2.