# ARROWs For Change

Women's and Gender Perspectives in Health Policies and Programmes

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### Reproductive Cancers: Women's Access to Screening Services

The development and implementation of National Reproductive Cancer Screening policies and programmes is an urgent priority in the area of reproductive health in Asia and the Pacific. Most women in both industrialised countries and poorer countries of the region have never had a pap smear test for cervical cancer or any education on how to do a breast self-examination to detect breast cancer. Without access to early detection methods, women are reported to be seeking treatment for cervical and breast cancer too late, when the disease is already at an advanced stage. Why is this happening and what are the solutions?

#### A Growing Concern

Globally, breast cancer is the most common cancer for women with a current total of 910,000 new cases per year, more than half of these cases being in industrialised countries.1 Incidence of breast cancer is increasing, particularly in countries which are industrialising. In Australia, for example, one in 13 women will suffer from breast cancer and for India, one in 50 can expect to get the disease. The Singapore incidence rate has increased from 27 per 100,000 people in 1980 to 39.3 per 100,00 people in 1990.2

Cervical cancer cases and deaths, however, have declined remarkedly in many industrialised countries due to implementation of extensive screening programmes. Globally, a total of 525,000 new cases are reported annually of which there are 247,000 deaths. Eighty per cent of women with cervical cancer are in developing countries where effective screening programmes are yet to be implemented.3

In Asia and the Pacific, in industrialising South East Asia and East Asia, more women now die from breast and cervical cancer than from pregnancy and childbirth. In Singapore, for example, WHO figures show the maternal mortality rate is 4.1 (1995) while the breast cancer mortality rate is much higher at 15.1, and even the cervical cancer mortality rate is 6.7 (1994). Japan has similar data for breast cancer although deaths from cervical cancer are now less than maternal deaths.

#### Lack of Access and Barriers

Although it is obvious from mortality and morbidity figures that reproductive cancer screening and treatment are a critical component of reproductive health services, data on screening could not be obtained from Country Health Profiles compiled by UN Agencies or from



women NGOs. This is because little or no evaluation of the extent of screening programme coverage has been done, which in turn is related to the absence of a national screening policy or programme to evaluate, and a lack of respect for women's total health needs.

Why do women not have access to screening? For poor countries in Asia, it is very likely that such services do not exist as even basic childbirth services and clinic infrastructure are not vet available for most women. Services do exist in better-off South East Asian countries and East Asia. but how often do women use them?

If screening services exist but there is low use. what are the barriers? Some of the barriers reported in Asian research studies are cultural insensitivity; inadequate information and education efforts to tailor communication/messages to the women who are most in need; insufficient consultation with women on what they want and need; the unsuitability of the gender of service providers; discomfort of the pap smear process; lack of understanding on preventive health care and the consequences of not being screened; and unfamiliarity and fear of medical procedures, particularly for women who have given birth at home within the comfort of a traditional health care setting. To what extent have policy makers and health service providers really tried to overcome some of these barriers? If the infrastructure of clinics, equipment and cytology labs plus trained personnel are not available for pap

smear screening, then health resources for reproductive health must be increased. Pap smear screening should be seen as a basic reproductive health service for women to which they have the right of access.

## Provision and Promotion of Screening Services

The Beijing Platform For Action recommends that governments: "Establish and/or strengthen programmes and services, including media campaigns, that address the prevention, early detection and treatment of breast, cervical and other cancers of the reproductive system" (para. 107 [m]).

Government Ministries of Health and other service providers which have screening services which are poorly utilised, need to carry out studies to find out why. Lessons can be learned from other countries, particularly Australia, which has a sizeable number of non-English speaking migrants with similar cultural backgrounds to women of Asia and the Pacific. Some of these lessons are:

- Women often prefer examination by a woman doctor with whom they are familiar. This is because it is expected that women doctors will promote more respect, reassurance and privacy in the screening process.
- The concept of prevention of disease is not part of all cultures and thus needs more explanation.
- Utilising social community networks as communication channels is effective when addressing cultural barriers.
- Media promotion is critical—broadcast and print—but hard-to-reach groups of women (e.g. rural women and older women) should be asked what media they more commonly use.
- For industrialising countries, the role of the general practitioner is critical. Women listen when the doctor advises them to have a pap smear or mammogram. The general practitioner needs to encourage screening, teach breast self-examination, and promote pamphlets and posters to support these messages.
- The efficacy of traditional methods of healing breast cancer and cervical cancer needs to be studied and the results widely disseminated.

#### Access to Treatment

Besides screening programmes, an equally important issue is the adequacy of women's access to treatment services for reproductive cancers. Very little information is available on this in Asia-Pacific. Generally, it appears that radiotherapy as one basic treatment option is available only in capital cities and thus women must travel very far and incur heavy financial costs. This was the situation prior to the last few years even in Malaysia, a country praised for the

adequacy of its primary health care services.
Radiotherapy is now available also at state level.
Waiting lists for initiating treatment in government hospitals are several months long however. In Lao PDR, radiotherapy is not available at all and the few women with financial means must travel to Thailand. In northern Viet Nam, this service is provided only in Hanoi at the Oncology Institute. It is imperative that more resources, effort and concern are invested urgently by governments for screening and treatment programmes for women's reproductive cancers. The neglect of this area of women's health is contributing to the unnecessary mortality of women and the suffering of their families, especially the poor.

References:

<sup>1</sup> WHO press release "World Health Organization warns of growing 'crisis of suffering'" <a href="http://www.who.ch/whr/1997/presse.htm">http://www.who.ch/whr/1997/presse.htm</a>

<sup>2</sup> C.H. Yip, E.H. Ng. 1996. "Breast cancer—a comparative study between Malaysian and Singaporean women". Singapore Medical Journal Vol 37: 264-267.

<sup>3</sup> WHO Press release "Pap Cytology Screening: Most of the Benefits Reaped?" <a href="http://www.who.ch/press/1997/pr97-25.html">http://www.who.ch/press/1997/pr97-25.html</a>

ARROWS For Change is published three times a year and is a bulletin primarily for Asian-Pacific decision-makers in health, population, family planning, and women's organisations. It provides: ◆ Women's and gender perspectives on women and health, particularly reproductive health ◆ A spotlight on innovative policy development and field programmes ◆ Monitoring of country activities post-ICPD, Cairo and post-FWCW, Beijing ◆ A gender analysis of health data and concepts ◆ Resources for action.

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#### Accessibility of Breast and Cervical Cancer Services in Malaysia

Malaysia's reproductive cancer treatment clinics are advanced and widespread. Mortality from breast and cervical cancer, however, is still relatively high because cancers are not detected early enough. This is a report based on interviews with medical specialists and women who have or have had reproductive cancers.

In Malaysia, breast cancer mortality has risen from 147 deaths in 1985 to 263 in 1993 and 297 in 1997.1 Trends in cervical cancer mortality had shown a decline from 163 deaths in 1985 to 122 in 1993. However, the figure crept up to 146 in 1997.2 Without a standardised, decentralised, extensive national cancer registry, only about one-third of deaths in Malaysia are medically certified. Thus, experts believe the incidence and mortality rates for both diseases are likely to be much higher than reported.

Malaysia's first nationwide, government cancer prevention campaign in 1995, stressed early detection of breast cancer by promoting breast selfexamination (BSE) and yearly examination by medical professionals for women aged 20 and above. All nurses, including those from rural villages, were trained in breast examination and supplied with models with which to teach BSE. Breast cancer clinics have now been set up at government general hospitals in all Malaysian states and examination is available on request at all government health facilities. In 1995, the pap smear eligibility guidelines were also amended to include all women (married and unmarried) who are sexually active or have been sexually active between the ages of 20 and 65. Pap smears are free and available at most government health facilities but not at village clinics.

Despite Malaysia's extensive health care infrastructure and modern medical facilities, the majority of women still present themselves at advanced stages of both diseases. A study done between 1993 and 1996 by Dr. Ibrahim Wahid and Dr. Yip Cheng Har at Kuala Lumpur's University Hospital revealed that 35 per cent of their breast cancer cases came with stage three and four cancers, which have low survival rates. Ninety-three per cent of these women had a breast lump with a staggering mean size of 5.3 centimetres.3

According to a counsellor from the Breast Cancer Welfare Society and a breast cancer survivor herself, "Cultural taboos surrounding the touching of our own bodies hinder women's chances of finding a lump early or going for a smear. During counselling sessions, women often express the fear that their husbands will leave them if they lose a breast or their reproductive organs as this renders them less feminine and functionless. Unfortunately, an alarming

number of women refuse mastectomy in the face of death as their husbands will not allow such a 'mutilation'. Many also turn to traditional methods first, such as herbal preparations"

Dato' Dr. Suseela Nair (consultant breast surgeon) aptly remarked, "Many of my patients say they don't have time to examine their breasts or go for regular check-ups and smear tests. The women tend to feel that other things are more important than looking after their health, like their families, houses and work". Women often do not feel that they have a right to this kind of preventive care. Moreover, it is not just the women themselves who feel they are not entitled to such services—doctors and nurses have been known to refuse requests for pap smears by women who are unmarried.

According to those interviewed, mammography, breast examination and pap smears continue to be carried out on a case to case basis despite existing guidelines. They believe this is because few frontline providers, including general practitioners, are taking proactive steps in the dissemination of information about these vital services. In turn, women are not empowered with the knowledge that they need to seek out services. Highrisk groups such as older women are difficult to target without a population-based programme as they are unlikely to visit family planning or mother and child health care clinics where the tests are readily available.

Therefore, Malaysia needs a standardised, wide-reaching national cancer registry to be implemented in order to determine the true incidence and mortality rates of breast and cervical cancer for her women. Studies need to be undertaken to find out how many women have ever performed BSE, had a breast check, mammogram and pap smear. Extensive research must also be carried out at grassroots level to determine how much women know about reproductive cancer risks and their own perceptions of the barriers to accessing services. Only then can the barriers for women and different cultural groups be identified and addressed, and the lives of many who needlessly suffer, be saved.

#### References:

- <sup>1</sup> Department of Statistics, Malaysia.
- <sup>2</sup> Department of Statistics, Malaysia.
- <sup>3</sup> Ibrahim Wahid. 1997. "Breast Cancer in Malaysia: A Survey of Women with Breast Cancer in the University Hospital Kuala Lumpur", World Conference on Breast Cancer, Kingston, Ontario, Canada, July 1997.



## PROGRAMME

#### New Zealand's Cervical Cancer Screening Programme

New Zealand's National Cervical Screening Programme (NCSP) was established in 1990 by the Department of Health. The current policy document encompasses the entire process of the formulation, implementation and evaluation of the screening programme. The first of its kind in New Zealand, the policy is guided by innovative and reformist principles: a women-centred approach, equal health status and access for Maori and Pacific Island

people as well as equity, efficiency, safety and acceptability in all decisions for the allocation and implementation of services for women.

The NCSP is a significant step for women's equality in health programmes and policies as it recognises the diverse needs of all women as perceived by women themselves. Social, economic and cultural barriers to participation in cervical screening as articulated by women are also addressed. Maori women are represented and catered for separately within the programme to ensure their different health needs are met. Women from the target community and women's interest groups were part of the development process and continue to be involved in evaluations of the scheme. The success of this approach to women's

health is evident in that New Zealand has now managed to enrol over 85 per cent of eligible women in the programme and can expect to see reductions in both the incidence and mortality from cervical cancer by the year 2000.

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#### Who Should be Screened?

All women between the ages of 20 and 69 who are sexually active or have been sexually active, excluding those who have had a total hysterectomy for a benign condition with a previous normal screening history, should be offered screening every

three years. This includes women of all ethnic groups, lesbians and women with disabilities. Women should have a second smear after one year if they have never had a smear before or if more than five years have passed since their last smear. After two negative smears, screening should be repeated every three years. Within the eligible population there are three priority, high-risk groups: mid-life and older women, Maori and Pacific Island women. There is an

average charge of 30 New Zealand dollars (\$US 20) for a smear although low-income women and priority groups may pay half of this or nothing at all.

#### Objectives of the NCSP

Six specific aims of the programme are identified by the policy. In addition to reducing mortality rates from cervical cancer, these include:

- No more than 30 per cent of invasive cancers detected should be beyond Stage 1 at the time of detection by the year 2000.
- Reducing cervical cancer incidence in women from 12 per 100,000 women (1989–1993) to below 8.6 per 100,000 or less by the year 2005.
- Reducing incidence of cervical cancer in Maori women from 29.8 per 100,000 (1989–1993) to below 11 per 100,000 by the year 2005.

## A Women-Centred Approach

Through ongoing consultations with women from the target community and women's NGOs, the Ministry of Health aims to find out what women want and need from a cervical screening programme in order to maximise participation. As a result, the current policy states that, "The service must acknowledge and meet women's needs and remove any barriers to their participation. . . the NCSP should take into account the range of factors identified by women". An example of this in practice is women now have access to a smear taker of choice such as a female

smear taker of their own cultural group (smear takers can be a general practitioner, nurse, midwife, trained layperson or medical specialist).

#### Overcoming Cultural Barriers

Culturally appropriate practices are an integral part of the programme policy. In line with the Ottawa Charter (1986) and Maori beliefs, the NCSP encompasses a holistic approach to health care. Service providers are educated about barriers perceived by specific cultural groups of women and ways to tackle them. As a result, the policy stresses the need for Maori and Pacific Island women to have access to training as smear takers and educators so that the delivery of service is culturally appropriate. A national Maori coordinator was also appointed by the Ministry of Health in 1994 after repeated requests from Maori women.

#### Health Education

Health promotion and education strategies are addressing the lower rates of enrolment of women over the age of 40 by dispelling the misconception that the test is only necessary for younger women or those who are currently heterosexually active. The NCSP is examining ways to promote primary prevention and health education to young women. Health promotion strategies are also addressing the barriers for other groups such as lesbians, sexual abuse victims, women with disabilities and Asian women. Strategies include media campaigns, workshops, booths in shopping malls, sponsored coupons on the back of supermarket dockets which give a discount, banners across high streets and notices in every prescription dispensed.

#### Efficient & Sensitive Methods

Once a pap smear is taken and analysed, the result is entered on the National Cervical Screening Register against the woman's details. The register is the key management tool of the NCSP as it forms a link between a woman, her smear taker, lab and treatment services, and assists with personal health management.

The confidentiality of all participants is strictly guarded by the provisions of the Health Act 1956 Section 74, the Privacy Act and codes of practice. The National Kaitaki Group (for Maori women) and the Pacific Women's Data Management Group govern the release of data thus honouring these groups' wishes for self-determination.

Local NCSP sites send an initial letter to women within five working days of receipt of a normal smear result. If the result is not completely normal, the letter from the registrar is withheld to give the smear taker the opportunity to inform the woman of her result. The NCSP also reminds women who

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#### THE SCREENING PATHWAY

Identifying the eligible population

Health promotion and education

Smeartaking

Smear reporting and notification of results

Management of women with abnormal smears

Coordination, monitoring and evaluation

are three months overdue for a smear.

To facilitate the sensitive and efficient followup of abnormal smears, guidelines for the management of abnormal results were developed in 1990 and the register tracks such women closely. These include the maximum waiting times for women referred to colposcopy (diagnostic examination of the vagina and cervix using a lighted magnifying instrument to find suspected abnormal cells—it is often combined with cervical biopsy).

#### Monitoring & Evaluation

To ensure the objectives of the policy are achieved, the Ministry has begun an evaluation of the NCSP's provision to priority groups and other subpopulations, evaluation of the NCSP's acceptability to consumers, and evaluation of expenditure on the NCSP. In doing this, NCSP is required to consult with Maori and Pacific Island professional and interest groups, such as the National Council of Women. Monitoring is carried out for quality assurance of service delivery, assessment of providers and evaluation of processes and outcomes along the screening pathway.

#### Source:

This article was written based on the publication, Ministry of Health, New Zealand. June 1996. National Cervical Screening Programme Policy. 47 p. KD

## Monitoring

#### Cambodia

As a follow-up to Beijing, the Women's Affairs Ministry which was established in January 1996, incorporated into their Action Plan four priority areas. These are Women and Education, Women and Health, Economic Development, and Women and Legal Protection. The Ministry proposed an Abortion Law in 1997, which formalises the need to ensure that women actually request for and agree to an abortion. Under this law, abortions must be performed only in hospitals, health centres, and in public or private maternity clinics by medical doctors, medical assistants or midwives. The law also states that those authorised to carry out the abortion must first provide proper counselling to the woman concerned. Abortions can only be carried out for pregnancies that are less than 12 weeks. For pregnancies which are more than 12 weeks, abortions can only be carried out if the diagnosis shows that the pregnancy is abnormal, growing unusually or creates a risk to the woman's life; or if after birth, the child can have a serious incurable disease; and in the case of rape. The Ministry has also given priority to supporting legal action in domestic violence cases. A draft law has been sent to the Prime Minister for approval. With this law, domestic violence will no longer be viewed as an internal household problem.

Source: ARROW's Field Visit to Indochina

#### Japan

The Japanese government has not issued any new policy statement recently on sexual and reproductive health rights. The government's Headquarters for the Promotion of Gender Equality Society headed by the Prime Minister, published the 2000 Plan of Gender Equality Society in February 1996. This serves as Japan's National Plan of Action after Beijing and Cairo. In relation to this, the Law for Formation of Council on Gender Equality was newly enacted in April 1997, and the Council is placed under the Office of the Prime Minister.

Japanese women's NGOs have identified key priority areas to target in view of the Beijing Platform for Action, such as licensing of the low-dose oral contraceptive; abolishing the Criminal Abortion Law and the Law for Protection of Mothers' Bodies. Other priority areas include establishing new laws for women's reproductive health rights; prohibiting violence against women; and prohibiting child abuse, including prostitution. Priority will also be given to establishing facilities for information, counselling and services on reproductive health and rights.

#### Lao People's Democratic Republic

In preparation for the Fourth Congress on Lao Women in 1997, the Lao Women's Union worked towards a gendered approach to policy and services for women. This was carried out in line with the Beijing Platform for Action, the Convention on the Elimination of All Forms of Discrimination against Women and the Convention on the Rights of the Child. Targetted areas were literacy rates for women; infrastructure development to cater for social, economic, health and educational needs of rural women; as well as economic growth and political and social stability. Due to the reformed economic programme introduced recently, measures are also being developed to overcome obstacles to achieving the Union's targets. For example, the emphasis of the economic programme is on rural development and maximising human resource development. However, the government of Lao is already facing a severe shortage of trained and skilled health staff. This in turn will effect the quality of health service delivery.

The Union is also working in collaboration with UNICEF and UNFPA to improve conditions for women and in guiding women to participate in national development areas, particularly in improving access to resources in regards to personal and family well-being. The areas being targetted are the birth spacing programmes in five provinces; knowledge and skills development; access to emergency food resources and essential medicines, and credit. For example, in the last three years, women in approximately 390 village communities have successfully established revolving fund microcredit facilities with funding assistance from UNICEF National Committees of the Netherlands, New Zealand and Japan. Training in revolving fund credit programme management was also provided to the communities. Furthermore, 40 rice banks have also been established in poorer communities.

After Beijing, the government gave priority to women's activities. In the 1996 Resolution of the 6th Party Congress, the government issued a directive to strengthen the capacity of the Women's Union to: implement and discuss the Platform for Action; discuss in the seven regions of Lao, the administration of the Union; identify the obstacles to women's advancement in line with the Beijing recommendations; discuss the Women's Convention and the Convention on the Rights of the Child; report to the government; and advise on policy decisionmaking. With support from UNIFEM, the Union is implementing its activities and enhancing its capabilities and capacities. UNIFEM is also carrying out gender training activities for the Union and government officials of high ranks. The Union is also working closely with UNFPA on follow-up activities



after Cairo. The government is currently finalising a population policy, which includes provisions for a birth spacing programme.

#### Sources:

1. WHO Regional Office for the Western Pacific, 1997. Women in Development: A Position Paper. Manila: WHO. 2. ARROW's Field Visit to Indochina.

#### Niue

Since Beijing, the primary goal for Niue has been to meet the needs of the women and thus, post-Beijing programmes have been planned to fulfill these needs. Activities included two workshops to familiarise women with the Women's Convention; a post-Beijing workshop, with women representing their various villages and Niue's delegation to Beijing as resource people; dissemination of information through radio and television on the Twelve Critical Areas of Concern of the Beijing Platform for Action; a business workshop to refine women's management skills; and a women's rights workshop. The Community Affairs Department had incorporated economic empowerment assistance, a women's development programme and the handicraft symposium which includes a business skills workshop on marketing, costing and financial management. The dissemination of information through the Community Affairs Department will be carried out through a newsletter, radio programmes, educational television programmes and information sharing.

Source: South Pacific Commission, 1997, Seventh Triennial Conference of Pacific Women: Report, Noumea. New Caledonia, 16-20 June 1997.

#### People's Republic of China

Since Cairo, reproductive health has become a major topic of discussion among those working in the areas of family planning, population and the social sciences. Although a formal reproductive health document or policy has not been issued, reproductive health has been given importance in speeches given by the head of the State Family Planning Commission. The State Family Planning Commission has chosen five provinces in the whole country as the experimental sites to improve the quality of care of family planning services. Fifty-five counties have also been chosen as test sites to provide a comprehensive reproductive health service package, which includes not only family planning services but other maternal health care services, for example, pre- and post-natal care. Many of the provincial family planning commissions have already decided to provide comprehensive reproductive health services in their implementation plans.

#### Asian and Pacific **Development Centre**

The Gender and Development Programme (GAD) of the Asian and Pacific Development Centre (APDC) organised a sub-regional Consultation for Indochina and Mongolia on "Post-Beijing Implementation and Monitoring" in May/June 1997. Twenty-six participants from Cambodia, Lao PDR, Mongolia, Viet Nam and regional organisations, and national NGO Watch groups from Malaysia, Philippines and Thailand, attended the meeting. The consultation was a follow-up to the sub-regional workshops which were carried out by APDC-GAD during its preparations for the Beijing Conference, where technical assistance was provided to underserved sub-regions and countries facing economic transition, to assist them in their preparation of national reports for the Fourth World Conference on Women. The consultation shared particular problems of implementation in economies in transition and discussed the provision of technical assistance at sub-regional and national levels to strengthen GO national machineries and NGO organisational capacities. Post-Beijing implementation responses and the form of technical assistance and training on a sub-regional or national level which could assist in the effective implementation of the Global Platform for Action were also discussed. APDC will bring out a detailed report of the proceedings which will be distributed in the region.

Source: APDC, Malaysia

#### Calling for Country Updates!!

We are urging national NGOs or individuals in Asia-Pacific countries to write to us and share your country's efforts to implement the Cairo and Beijing recommendations, particularly relating to women and health. If you are keen in sharing, please get in touch with ARROW for more details.

#### **National Contributors**

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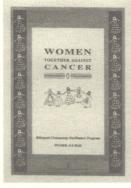
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#### From the Documentation Centre

Anti-Cancer Council of Victoria, 1992, Women Together Against Cancer: Bilingual Community Facilitators Program, Work Guide, Carlton South: Anti-Cancer Council of Victoria. 202 p.

This work guide was developed by trainers and participants of the first "Women Together Against Cancer" facilitator training programme which is part of the Anti-Cancer Council's migrant women's project. The participants have been prepared as bilingual community facilitators to provide information about



cancer and its prevention to their own communities. The aim of the training programme is to: 1) provide accurate information about cancer, cancer prevention and early detection; 2) provide this information in a sensitive manner which recognises and acknowledges the life experiences and cultural values of the group and the community; and 3) work with the community in a way that enhances active involvement through discussion and the sharing of information and experiences in a non-threatening and comfortable setting.

The guide contains an administration section, steps to working with groups, resources and services lists, in addition to the following four model session plans: 1) What is cancer; 2) Cancer causes and prevention; 3) Breast health—breast changes; 4) The Pap test—why we need it. The administrative section includes information on how to plan and organise the training sessions. Steps to working with groups include many practical tips on starting, warm-up exercises, energisers, and finishing activities. Each model session is structured in seven steps:

- 1) Introduction of self; 2) Warm-up exercise;
- 3) Background information; 4) Sharing feelings and beliefs; 5) Basic facts; 6) Major information;
- 7) Ending, including answers to questions, additional information, and extra activities. The guide concludes with the extensive Australian services listing. This work guide is a good model and tool to develop community-based cancer information and training programmes and is presented in a folder.
- Source: Anti-Cancer Council of Victoria, Keogh House, 1 Rathdowne Street, Carlton South, Australia 3053.

Coney, Sandra (ed.). 1993. Unfinished Business: what happened to the Cartwright Report? Auckland: Women's Health Action. 192 p.

These "writings on the aftermath of the unfortunate experiment at National Women's Hospital" discuss

the progress on the recommendations of Judge Cartwright's Report of the Cervical Cancer Inquiry five years after its publication in 1988. A research programme on carcinoma in situ (CIS) of the cervix, started in 1966 at the National Women's Hospital in Auckland, had resulted in a number of women developing invasive cervical cancer.

The chronology of events is followed by an analysis of outcomes, five years after release of the report, including background information on the research programme, the resulting inquiry and report. It highlights the recommendations and looks at their implementation. The inquiry had a significant positive effect on women and women's health groups. Health care consumers have become more assertive and aware of their rights, and health professionals' awareness of issues such as informed consent has been heightened.

Some other aspects highlighted by articles include the view from the former Minister of Health, the legal proceedings of the women who suffered from cancer as a result of the experiment, the difficulties of patient advocacy, the experience of chairing an ethics committee, the consumer perspective,



nurses' response to the report, the meaning of informed consent, developing treatment protocols, and the impact of the report on Pacific Island women. This case study is a valuable lesson for women's health advocacy, giving a comprehensive view of the issues involved.

■ Source: Women's Health Action, PO Box 4569, Auckland, New Zealand.

Fonn, Sharon; Klugman, Barbara; Dehaeck, Katrien. 1993. Towards a National Screening Policy for Cancer of the Cervix in South Africa. Johannesburg: The Centre for Health Policy. Department of Community Health, Medical School, University of the Witwatersrand. 20 p.

This book reviews the debates about the effectiveness of pap smear screening programmes in lowering cervical cancer mortality, and the related question of the frequency of screening intervals. The authors propose that screening for cervical cancer should be integrated into the health service in South Africa in the framework of a National Screening Policy, which is accompanied by a five-year pilot study. The pilot study should provide answers to such questions as costing, quality of pap smear tests, screening interval and education about cancer of the cervix. The policy should implement five components: 1) Creation of consumer demand

through education and publicity with an information campaign on cervical cancer and the role of pap smear test; 2) Health personnel training by the Department of National Health and Population with a "train the trainers programme"; 3) Pap smear tests as a routine of the national health service; 4) A women's health card, a patient-kept record to help in keeping track of pap smear tests and results, as well as on immunisation; 5) A national database to monitor the pap smear test programme, and to serve as the basis on which publicity and programme strategies could be adapted.

Source: The Centre for Health Policy, Department of Community Health, Medical School, 7 Yorkroad, Parktown, Johannesburg.

O'Shea, Maggie; Farnan, Sue. 1996. Breast For Me: Breast Health Education for Women with Disabilities. St. Footscray, Victoria: Women's Health West. v.p.

This visual and multi-lingual resource kit for women, carers and health professionals about how women with a physical, psychiatric or intellectual disability can look after their breasts consists of a video (25 min.), slides and picture cards, written information, and information brochures and pamphlets, which can be used in a group setting. The video, intended as the starting point and focus, has three sections: 1) Our bodies, our choices; 2) Breast selfexamination and breast examination by a doctor or women's health nurse; and 3) Having a breast x-ray (mammogram) at BreastScreen. The viewing of each section should be followed by a group discussion. The picture cards are designed to reinforce the information in the video. They are particularly useful for women with intellectual disabilities. The slides summarise background information about breast health for women with disabilities and can be used as presentation tools to raise awareness of health professionals.

The written information is intended primarily for carers and health workers in preparation for education sessions with women with disabilities. It is complemented by health information brochures and breast screening registration forms. These familiarise women and support workers with all aspects of breast health care and the consent process. This resource kit has been developed in Australia where health care for people with disabilities is well organised, and therefore, may not be fully applicable in all Asian-Pacific countries.

Source: Women's Health West, 60 Droop St. Footscray, Victoria 3011, Australia.

O'Sullivan, Sue. 1996. "Mystification, medicalisation and prevention: Some questions about breast self

examination". Healthsharing Women Vol. 6, No. 5. pp. 1. 3-6.

The author takes a critical look at preventive measures concerning breast cancer, which is the most commonly occurring cause of cancer deaths among women in Australia. Research on Breast Self Examination (BSE) tends to focus on three areas: uptake of BSE by particular groups; increasing "compliancy" among women; and methods of teaching women the correct technique. In Australia. efforts have been made to teach BSE to hard-toreach women, rather than to white, married, educated, younger women who are currently the most likely to learn about and practise BSE. The overall message of most materials on BSE is: "Early detection is your best protection". However, breast cancer is not a single, straight forward disease, but a number of types and combinations of diseases with variable prognoses which do not necessarily depend on early detection.

BSE, seen in a broader context, shows some contradictions. BSE is carried out alone at home, and as soon as a lump is discovered, women have to hand themselves over to a hierarchical, male dominated, medical-technical profession, a system that often disempowers women. The fear of women of loss or mutilation of their breasts also may play a positive or negative role in BSE. The author suggests to encourage self-directed breast exploration at a much earlier age to broaden the parameters of breast health, including physical knowledge. Breast cancer is relatively uncommon among younger women. Unfortunately, it is more virulent and less responsive to treatment in younger women.

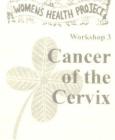
To address breast cancer within a wider framework, it is necessary to look at social, economic and cultural influences on health and illness. Breast cancer activism and continuing analysis of women's health concerns, focussed on the specificity of breast cancer, will help to unravel the dualistic approaches and ironies of BSE.

■ Source: Healthsharing Women's Health Resource Service, GPO Box 1160K, Melbourne 3001, Australia.

Women's Health Project. 1993. Cancer of the cervix. (Health Workshop. 3.) Johannesburg: Centre for Health BAG Policy, Dept. of Community Health, University of the Witwatersrand. 8, 24 p., 5

The third of the Health Workshop Packages consists of two booklets and five posters. The first booklet is a general

posters.



introduction to all workshops on different women's health issues developed by the Women's Health Project and designed to help women learn more about health. It includes guidelines for using the packages and gives tips on facilitating the workshops. The second part provides information on the topic, which in this instance is on cancer of the cervix. Each section of the workshop provides notes for the facilitator as well as information for the participants. Workshop sections are: Warming up; What are we going to do today?: Problem words: What is cancer?: Cancer of the cervix: the cause: How do I know if I have cancer of the cervix?; Story telling: Pap smears: Treatment of cancer of the cervix; and, What more can we do about cancer of the cervix? The publication provides a step-by-step approach to facilitating the workshop. It can be easily adapted for any kind of environment and also can be used to develop workshops on other women's health

■ Source: Centre for Health Policy, Department of Community Health, Medical School, 7 York Road, Parktown, Johannesburg.

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13th Asia Pacific Cancer Conference, Penang Malaysia, 17th-20th November 1996: Book of Abstracts. 648p.

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Women and Development Unit. 1995. "Up-in-arms over breast cancer: A toxic link?" Women's Health Journal: Latin American and Caribbean Women's Health Network, 1, pp.31-50.

CancerMondial: IARC Epidemiology Data <a href="http://www-dep.iarc.fr">http://www-dep.iarc.fr</a>

**International Union Against Cancer: UICC** International Directory of Cancer Institutes and Organizations, 6th ed.

<a href="http://www.uicc.ch/directory/">

OncoLink [by the University of Pennsylvania Cancer Center]

<a href="http://www.oncolink.upenn.edu">http://www.oncolink.upenn.edu</a>

#### ARROW'S PUBLICATIONS

ARROW. 1997. Gender and Women's Health: Information Package No. 2. Kuala Lumpur: ARROW. v.p.

Price: US\$10.00 plus US\$3.00 postal charges. Payment accepted in bank draft.

ARROW, 1996. Women-centred and Gendersensitive Experiences: Changing Our Perspectives, Policies and Programmes on Women's Health in Asia and the Pacific, Health Resource Kit, Kuala Lumpur: ARROW. v.p.

■ Differential pricing. For more information, please contact ARROW.

ARROW. 1994. Towards Women-Centred Reproductive Health: Information Package No. 1. Kuala Lumpur: ARROW. v.p.

Price: US\$10.00 plus US\$3.00 postal charges. Payment accepted in bank draft.

ARROW. 1994. Reappraising Population Policies and Family Planning Programmes: An Annotated Bibliography. Kuala Lumpur: ARROW. 101 p.

Price: US\$5.00 plus US\$3.00 postal charges. Payment accepted in bank draft.

#### **ARROW Documentation Centre Service**

Information requests by telephone, in writing (by mail, fax or e-mail) or through visits are welcome. A minimal fee will be charged for any service rendered.

#### Benign

Not cancerous, and does not invade nearby tissue or spread to other parts of the body.

#### Biopsy

The removal of a sample tissue, which is then examined under a microscope to check for cancer cells. When only a sample of tissue is removed, the procedure is called incisional biopsy; when the whole tumor is removed, the procedure is called excisional biopsy. Removing tissue or fluid with a needle is called needle biopsy or needle aspiration.

#### Cancer

A term for diseases in which abnormal cells divide without control. Cancer cells can invade nearby tissue and can spread through the bloodstream and lymphatic system to other parts of the body.

#### Malignant

Cancerous.

Source: http://cancernet.nci.nih.gov/glossary.htm

#### Mastectomy

Surgical removal of the breast. There are various types of mastectomy, depending on the extent of the cancer. An operation may remove a lump part of the breast or the whole breast, lymph glands underneath the arm and sometimes the muscles of the chest.

Source: Shallat, L. 1995. "Up-in arms over breast cancer". Women's Health Journal: Latin American and Caribbean Women's Health Network.\*1/95, pp.31-50

Conservative segmental mastectomy is the removal of the peripheral tumours less than 3 cm without removing the whole breast and this is possible for Asian women whose breasts are generally smaller than Western women.

Source: Lim, S. 1996. "Saving the breast: The Singapore experience". Neoplasia. Vol 2, No 2, pp. 8.

#### Mammogram

X-ray of the breast, which uses low doses of radiation. A baseline mammogram is performed on healthy breasts usually at the age of 35 to establish a basis for later comparison. [Most guidelines recommend performing a first mammogram at the age of 50, unless at risk].

#### Oncology

The science dealing with the physical, chemical and biological properties and features of cancer, including causes, the disease process and therapies.

Source: http://www.cancerhelp.com/ed/glossary.htm

#### Reproductive Cancer Mortality in Women

Globally, women are increasingly reported to be dying from reproductive cancers. Despite this, estimates of mortality and incidence of reproductive cancers are available only for a few countries in the Asia-Pacific region. In most cases, only mortality data is available (see Table 1). However, lower cancer mortality data does not necessarily reflect a lower incidence rate, especially for developing countries where there is a serious lack of screening programmes and national cancer registries.

Breast cancer is noted to be the most frequent reproductive cancer in women. New Zealand, for example, has a high mortality rate of 33.3 from breast cancer (see Table 1), with a reported increase of 21 per cent in the last 30 years among both European and Maori women. 1 Years of delay to the start of a national breast screening programme and a high rate of pesticide use are some of the factors associated with the high prevalence rate.2 Japan with a mortality rate of 11.3, has also recorded an increase in breast cancer by 25 per cent since 1950. This increase has been attributed to lifestyle changes such as low birth rates and high consumption of fat in the Japanese diet.3 In Viet Nam, 30 per cent of cancer cases in women are breast cancer and the survival rate is only ten per cent compared to 80 per cent in most industrialised countries. Changing childbirth patterns, cultural barriers and long hours of work which prevent women from seeking medical help are some of the factors associated with the low survival rate.4

Cervical cancer accounts for three to five per cent of all deaths among women globally. Approximately, 80 per cent of these cervical cancer cases are not diagnosed until they are at an advanced stage. Incidence and mortality rates for cervical cancer can be decreased significantly with early screening for all women beginning at the onset of their sexual activity. Cervical cancer is reported to be the leading cause of death among the Pacific Island women, with Fiji at 12.5 (see Table 1). Information about Fiji's incidence rate on cervical cancer is not accessible but health workers have described it as being of epidemic proportions. The latest figures from Fiji's Ministry of Health, states that cervical cancer accounted for 37 per cent of all cancers in women with an age standardised (where age is considered having a powerful influence on the risk of cancer) incidence rate of 114.6 per 100,000 women, a rate approximately four times that in Thailand and more than five times that in the Philippines.5

Ovarian and uterine cancers are also common cancers of the reproductive system. Unfortunately, there is a lack of statistical data in this region, as most countries do not have a national cancer registry. However, it has been reported that the

Table 1. Mortality Data for Reproductive Cancers of the Breast and the Cervix

		Breast	Cervical
Australia	1993	29.5	3.6
China	1992	5.1	3.4
Fiji	1978	4.0	12.5
Japan	1994	11.3	3.0
New Zealand	1993	33.3	4.6
Philippines	1981	3.9	0.9
Singapore	1994	15.1	6.7
Sri Lanka	1986	1.6	0.4
Thailand	1987	0.8	0.5

Note: The countries featured are the only countries in the region where data is available through the Databank of the International Agency for Research on Cancer (IARC) website.6

incidence of ovarian cancer is on an increase but not as alarming a rate as breast or cervical cancer. For example, Japan has recorded an increase in ovarian cancer incidence from 3.5 per cent in 1955 to 10.5 per cent in 1985.

In light of the growing increase of reproductive cancers in women, there is a great need for valid and accurate estimates of the incidence and mortality rates for these cancers. It is imperative therefore, that national cancer registries and formal screening policies and programmes, are put in place for such estimates to be obtained. Furthermore, in the absence of screening programmes in poorer countries, primary prevention should take place through health education. By informing women on the early warning signs of reproductive cancers and encouraging them to seek medical examinations and treatment, women would not have to die needlessly.

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- <sup>3</sup> Wynder, E. L. [et al.]. 1991. "Comparative epidemiology of cancer between the United States and Japan: A second look". Cancer. Vol 67, No 3. pp. 746-763.
- <sup>4</sup> Hoai Duc, N.T. 1997. "Breast cancer in Vietnam", [paper presented at the] World Conference on Breast Cancer, 13-17 July 1997.
- <sup>5</sup> Fiji Ministry of Health. (1995). National Cancer Prevention and Control Programme Internal Report.
- <sup>6</sup> The World Health Organisation Databank and the rates are expressed as crude rates per 100,000 people. IARC website: <a href="http://www.iarc.fr">http://www.iarc.fr">.