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Te Kaunihera Wahine O Aotearoa

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Submission to the Ministry of Health on the Discussion Document: Towards a Cancer Control Strategy for New Zealand: Marahi Tauporo

The National Council of Women of New Zealand (NCWNZ) is an umbrella organisation representing 42 nationally organised societies. It has 34 branches spread throughout the country to which some 150 organisations are affiliated. NCWNZ also represents a number of individual women.

NCWNZ is grateful for this opportunity to be able to make a submission on this discussion document. Responses have been received from members of the Health Standing Committee and from individual branch members. Many of these women have been affected by cancer either as sufferers or taking care of others.

We are disappointed to think that we are still making submissions regarding this topic on similar lines to those we have made in the past.

In 1986 we wrote to the Minister of Health to draw his attention to NCWNZ's long-held policy, "that more finance be allocated to the development of preventive health services and to research in this field." In that same letter that we commented on the need for funding and greater publicity for education leading to the prevention of alcohol abuse and our preference for preventive strategies rather than 'high tech' or 'glamour programmes'.

In 1987 we were urging the Minister of Health to, "give priority to positive health promotion and preventive measures, including all possible steps to reduce cancer in women, in particular the promotion of regular cervical smears and of breast examination at no cost to the individual." It is interesting to note how similar this is when looked at as part of the "cancer control continuum" in this document. It seems that while such services are now available they are not being accessed by large sections of the community. More must be done both by the service providers and members of the community.

In 1988 we noted with concern matters relating to the depletion of the ozone layer and its links with increased numbers of melanomas and other issues.

In 1999 a resolution was past calling on the Government to establish a cancer control strategy and it is with this in mind that we congratulate you for this document.

It is commendable that the purpose, principles and goals of this strategy are intended to be enduring and that there is intention to coordinate prevention, screening, diagnosis, treatment, rehabilitation, palliative care and research. Improving alliances with health professionals and voluntary groups, both government and non-government, is also to be commended. We agree that the principles (page 12) are suitable and that the goals (page 13) are appropriate for guiding the strategy.

To achieve these goals, obviously, health services need to be adequately funded. Reducing the incidence and impact of cancer needs social and public health **evidence based** initiatives. The implementation of the strategy needs initiatives that facilitate good quality evaluation of the effectiveness, and monitor the impact on health inequalities.

SPECIFIC COMMENTS
Part One: The High Level Framework

Question 1 (p4)
Do you consider that the principles are suitable for guiding the New Zealand Cancer Control Strategy?
Yes with some modification.

Our members felt the principles are all admirable but some, e.g. equitable access, reduced inequalities and the right of informed choice, will need considerable improvement.

To provide people with adequate and clear information so that they may make choices that are truly fully informed it is important that all options and possible outcomes are given without bias.

Because there is so much variation in the way cancers develop in individuals, treatment is problematic. It will also take lengthy education, over decades to achieve an improvement in the incidence of this disease.

NCWNZ members expressed concern about the Ministry's ability to fund the total needs, not wishes, of a person and their family. This also raised concern with our group about whether the next, younger generation of consumers will become involved in voluntary services.

Question 2 (p5)
Do you consider the six goals are appropriate for the New Zealand Cancer Control Strategy?
Yes with some modification.

Members found that some of the goals, namely 3, "To improve timely access to effective and acceptable activities and services to control cancer." and 5, "To improve planning, co-ordination and integration of activities and services to control cancer." are not well worded. "To control cancer" should become "for those suffering from cancer".

Some goals will be unproductive without the attainment of others. e.g. reducing death and disability through effective screening and early detection becomes pointless unless there can be timely access to effective activities and treatment.

Rural women have commented that there is always a discrepancy between rural and urban services.

Our members assume that goal 5, "to improve the planning, co-ordination and integration of activities and services to control cancer" includes the frontline workforce and their on-going training, salaries and retention to carry these activities out.

All collected data should be shared with international researchers. Respondents understand that the National Cancer Register (kept by the Health Information Section of the Ministry of Health) does not record:

- Stage of disease at time of diagnosis
- Treatment received
- Outcomes
- Ethnicity (guidelines determining them)

NCWNZ members believe that there should also be separate registers for children, adolescents, Maori and Pacific peoples.

Part Two: Proposed Objectives and Actions

Goal 1: To reduce the incidence of cancer through prevention

Question 3 (p6)
Do you consider the proposed objectives are likely to lead to effective action to achieve this goal?
Respondents agree with the objectives insofar as they go but none of the 7 objectives are likely to succeed if under-resourced, i.e. funding and staffing. This also applies to questions 9, 15, 21 and 27, later in the document.

Objective 1 regarding the reduction of the number of people who develop cancers due to tobacco use is amenable to legislative change, i.e. controlling where it is acceptable to smoke, controlling the supply of tobacco products, and a higher 'tied' taxation would be sensible. The objective does not acknowledge the effect on others of second hand smoke, e.g. no smoking in anybody's workplace.

Positive results in reducing the number of people who develop cancers related to tobacco use, physical inactivity and obesity, poor nutrition, UV radiation, infectious diseases, alcohol use and certain occupations will depend on people's motivation to change their lifestyle habits and their community's preparedness for involvement in assisting in this change. Regular evaluation must continue as a requirement to get an accurate picture of the effects of changes.

People must expect to take responsibility for their own health.

Effective information and education programmes to help people realise the risks of developing cancer must continue. It may take a long time before an appreciable difference in incidence can be evaluated. The effectiveness of education programmes must continue to be regularly monitored.

Question 4 (p6)
Are there other objectives that should be included?
Acceptance that some cultural differences may prevent objectives being achieved, e.g. Maori/Island women not seeking breast cancer screening, treatment and surgery when needed. More encouragement for these women to attend is required.

NCWNZ supports close monitoring of research statistics to avoid unwitting exposure to newly discovered risks, e.g. medications such as Hormone Replacement Therapy.

The effects of pollution of the environment, e.g. traffic fumes, chemical spray drift, air conditioning, etc.

Question 5 (p7)
From your perspective, which of these objectives are the most important?
Those responding felt that all of the objectives were important but objective 1 relating to tobacco use, objective 2 physical inactivity and obesity, objective 4, exposure to UV radiation, and objective 7 occupational related cancers were regarded as of particular importance because of the numbers of people involved and the effectiveness of simple prevention methods, for example:

- Reducing smoking, particularly in young women, especially Maori and young Asian women;
- Encouraging regular exercise, such as daily walks;
- Encouraging sun protection;
- Rescheduling of school and sporting activities to avoid exposure at the hottest times of the day; and
- Workplace monitoring.

All the objectives are important to enhance and improve existing educational and information campaigns.

Question 6 (p7)
Which actions do you think would be most effective in meeting the objectives you consider most important?
Ensuring people are adequately informed of risks, e.g. Objective 4 "Reduce the number of people developing skin cancers due to UV radiation exposure." Continue and extend public health advertising about early recognition (needs accessible primary care) and advice on prevention. There is some evidence that some of the public regard sunscreen as their main protection and education needs to emphasise sun avoidance or

protective clothing (British Medical Journal, 2003; 326: 114-5). More preschoolers and junior pupils are wearing sunhats but many intermediate or secondary pupils are not.

A suggestion from respondents was to inform people about risks by having cancer victims speak at schools and Marae to tell their stories. These stories can be very powerful.

Attempt to discourage smoking and alcohol consumption in TV, films, movies, etc.

NCWNZ would support a ban on advertising of tobacco products and alcohol.

Promote smoke-free environments with no smoking indoors - air-conditioning recirculates smoke and bugs (aeroplanes).

Town planning should be involved in developing safe areas for cycling, walking, shaded areas etc.

Actively promote exercise with more sports venues with cheaper or free access.

Health promotion days should be continued and increased in community centres and marae including demonstration of meal preparation, promotion of breast-feeding to reduce the incidence of obesity in child as breast milk does not lay down permanent fat cells. Artificially fed infants who are overweight tend to remain so**.**

Use should be made of graphic advertisements of the fat content of various foods and the damage high levels of fat may cause. The message should be disseminated by use of pamphlets and posters, especially in schools.

Increased promotion is required of the risks involved in taking illegal drugs and the risks associated with sharing needles. Existing programmes may need to be enhanced.

Promotion of the use of green prescriptions should be increased throughout the country.

Continue to encourage family/whanau and peer support in all programmes.

Question 7 (p7)

Which organisations do you think should be actively involved in meeting these objectives?

- Ministry of Health
- Cancer Clinics
- Churches
- Employers. Workplaces could encourage workouts and offer reduced fee gym memberships.
- All health service providers
- TV, film and radio advertisers
- All schools and tertiary education institutions should set an example by providing healthier foods and shaded areas
- Marae/kaumatua/kuia, sporting, educational leaders
- ASH
- Cancer Society
- Maori Health Groups
- City and Local Councils
- Local Authorities
- Toi te Ora Public Health
- Marae-based Health Services
- Plunket Society
- Department of Labour, OSH
- Government Health Boards
- Government departments, especially health, education, social sciences, housing, commerce
- MAF, ERMA
- Local Iwi, etc.
- Citizens' Advice Bureau

Question 8 (p7)

Other comments?

The benefits of living a healthy lifestyle need to be promoted in a way that is acceptable to all sectors of society - it needs to be seen as a 'cool' way to live so people are happy to take responsibility for their own good health.

Healthy eating, Healthy Action should continue to be promoted in terms of overall health as well as a separate cancer reducing strategy.

NCWNZ members believe that 'healthy food' is often the expensive option. It is suggested that GST could be reduced on staple food items; milk not coca cola, bread not confectionary.

Examples should be set by MP's, "City Fathers" and sports people/heroes e.g. excessive eating leading to obesity and not indulging in excessive alcohol intake.

Goal 2: To reduce death and disability through effective screening, early detection and treatment.

"Objective 5" should be read as 'Objective 4'.

Question 9 (p8)
Do you consider the proposed objectives are likely to lead to effective action to achieve this goal?
NCWNZ members agree, provided that funding is adequate to improve on the present situation, and that it is used for provision of services and related staff rather than more management.

Screening mainly occurs in the primary health field and currently the funding available is inadequate in many regions. Some patients cannot afford medical costs for acute health problems, let alone "well patient health checks". Delayed recognition of cancer may lead to more distress, disability and more costly treatment. Providing access to good primary health care would go a long way to improving screening programmes. Guidelines by the various health professional Colleges would assist education of primary health providers.

NCWNZ's "Girl Talk" question regarding cervical screening asked what barriers young women had to having a screening test, and 'cost' was the highest on the list.

Concern was raised about the effectiveness of screening and whether the current screening activities are yielding appropriate information to further present prevention strategies.

Regarding genetic screening, the more that is known about predisposition to cancer the better will be the targeting of resources. The acceptance of this by the public needs further consideration, i.e. use of information for purposes for which it was collected only. NCWNZ does not approve of this information being used for insurance purposes, etc.

Many people are already concerned about the security of their personal information being held on National Registers/computers.

Several respondents expressed concern about women opting out of screening programmes because of the attitudes of professional health providers.

Performance of Cervical Screening Programmes in East Coast and Northland would not inspire confidence for Maori. NCWNZ has repeatedly supported the implementation of the Gisborne Enquiry recommendations.

Our members believe that Objectives 1, "To provide at a national level a systematic approach to cancer screening, familial risk assessment and surveillance to ensure their quality, acceptability and effectiveness." and 2, "Establish a process to assess the value of early detection of cancer other than that obtained through organised screening." are useless unless timely access to treatment is available and accessible in all areas.

Objective 5 "Provide people experiencing cancers access to the best available drugs, surgery and treatment technologies." will depend on adequate government funding.

Question 10 (p8)
Are there other objectives that should be included?
Establishing cultural acceptance within programmes to encourage Maori and Pacific Island women to accept preventive treatment. Programmes can't be effective without their active participation.

Identify and offer regular surveillance in a timely way to those with familial cancer, e.g. colonoscopy for familial polyposis, breast cancers, etc. Again, funding may be a barrier.

Develop clear public guidelines, timing for steps in diagnosis, surgery and follow-up treatments. Breast Screen Aotearoa is a good example of how to do this.

Question 11 (p9)
From your perspective, which of these objectives are the most important?
Objective 4 (Listed as 5). If you don't give access to the best available drugs, surgery and treatment technologies the other three will not be effective.

Question 12 (p9)
Which actions do you think would be most effective in meeting the objectives you consider most important?
NCWNZ supports proper funding of a service that puts the needs of patients before profits. While screening and familial risk assessments for early detection are vital they are of no value if access to the best available drugs, surgery and treatment technologies are limited by financial constraints. Lack of experienced staff will also be a constraint.

Other suggestions dealt with the promotion of the value of early detection and treatment. These included:

- Encouraging specialists to talk to groups positively about successful treatments.
- Free screening for public health issues on TV, in Theatres and free to air on Radio, both commercial and non-commercial. Members understand that health promotion is a costly exercise.
- Continue to promote personal responsibility for seeking advice if concerned about changed bodily functions, e.g., noting skin changes, unusual bumps in soft or deep tissue, pain, changes in bowel habits, etc.
- Encouraging all people to be enrolled with a health professional.
- Promoting quality care by developing clear public guidelines, timing for steps in diagnosis, surgery and follow-up treatments and ensuring that patients and their caregivers are kept up-to-date and fully informed.

NCWNZ is also concerned that there should be continued government commitment to adequately fund screening programmes so that accurate baseline data is accumulated and outcomes of interventions assessed.

Question 13 (p9)
Which organisations do you think should be actively involved in meeting these objectives?
- Ministry of Health
- Medical Schools and Associations
- Cancer Society
- Maori Women's Welfare League
- Marae groups and other community organisations including ethnic groups
- Cancer Control Trust
- District Health Boards
- Health education providers to provide high quality training
- Hospitals Private laboratories
- Private radiotherapy/oncology services
- Primary care givers e.g. GPs
- Funding Agencies so that we get on top of staffing issues, i.e. recruiting, training, retention.

Question 14 (p9)
Other comments?
Screening for genetic susceptibility requires great skill and sensitivity in identifying familial risk e.g. Breast Cancer, polyposis of colon. It is essential that experienced staff are retained and are there also to assist new staff.

Where new cancer treatment technologies are introduced it will be essential to show that we are gaining additional benefits as well as capacity over existing treatments.

A mechanism for data collection is the first step towards gathering worthwhile information. Privacy aspects and funding need to dealt with. An example of this is Breast Screen Aoteoroa.

Maori Health Professionals should continue to advise on culturally appropriate programmes to be used for Maori. Likewise, Pacific Island Health Professionals should also continue to advise on culturally appropriate programmes to be used for Pacific peoples.

It would be valuable to have family health history noted for infants born as a result of gamete donation, i.e. so that databases would be accurate. Privacy issues need to be considered as well as the rights of the child.

There must be organisation of, and accountability for reviewing programmes for all screening programmes.

Every endeavour must be made for the training and retention of the workforce providing screening, treatment, chemotherapy, radiotherapy and surgery.

Goal 3: To improve timely access to effective and acceptable activities and services to control cancer.

Question 15 (p10)
Do you consider the proposed objectives are likely to lead to effective action to achieve this goal?
Yes, NCWNZ recommends adequate funding at the appropriate level, i.e. to those providing treatment, support and rehabilitation for people with cancer and people caring for them. It should also be kept in mind that health professionals involved with cancer patients also need access to appropriate support from time to time.

Currently many Hospices are inadequately publicly funded and have to spend time fund raising. They also rely heavily on volunteers. Palliative care must be funded adequately otherwise too much time and effort is diverted to fundraising activities.

NCWNZ supports palliative care teams being multidisciplinary, including spiritual care (British Medical Journal, 2002; 325:1434-5). We note that Hospital chaplaincy funding has been recently threatened.

Our members feel that information about complementary and alternative therapies should be carefully handled as some actually may help, while others offer false hopes. Where such therapies are appropriate hard copy should be readily available in appropriate languages in schools, churches, community facilities, etc. Not everyone has access to the internet to gain such information.

Question 16 (p10)
Are there other objectives that should be included?
Our members recommend that there is seamless progression through providers, e.g. on discharge from hospital to home the provider is fully aware of what has gone before and the client is comfortable knowing that the care and treatment will continue.

Services need to be culturally appropriate for Pacific peoples. Smaller ethnic groups need to be given information about how to access culturally appropriate services.

Question 17 (p11)
From your perspective, which of these objectives are the most important?
Respondents considered that all are equally important.

Question 18 (p11)
Which actions do you think would be most effective in meeting the objectives you consider most important?
Culturally appropriate services should be provided for all major ethnic groups.

NCWNZ urge Maori and Pacific peoples to train as health professionals in cancer services and take advice also from their elders.

Optimise communication between providers to promote co-operation.

NCWNZ members believe that service providers must respect the patient's rights to pursue other healthcare options.

Information, in the form of fact sheets for patients and their families, about services available, appropriate treatment methods, care, complementary and alternative therapies, should be provided in English, Maori, Pacific Island languages, French, Mandarin, etc.

Hospices should be adequately funded.

There should be constant monitoring to detect gaps in the provision of acceptable activities and services to people with cancer and their families.

Question 19 (p11)
Which organisations do you think should be actively involved in meeting these objectives?

- Ministry of Health
- Marae
- Community
- Cancer Society
- Local support groups
- Palliative care groups
- Hospices
- Health Insurance Companies
- GPs, Specialists
- Cancer Nurses
- Iwi Health Services
- District Health Boards
- Consumers Organisations

Question 20 (p11)
Other comments?
Patients opting for alternative health care only should be required to sign 'disclaimers' that they rejected orthodox treatments.

Respondents expressed concern that funding of alternative therapies should not be at the expense of conventional therapies. Patients who choose such treatments should also be asked to pay for them.

Goal 4: To improve the quality of life for those living with, recovering from and dying of cancer.

Question 21 (p12)
Do you consider the proposed objectives are likely to lead to effective action to achieve this goal?
Yes if they are equitably and adequately funded.

NCWNZ hopes that Objective 2, "Ensure that all survivors of childhood cancer receive timely and ongoing support and rehabilitation, including early identification of and intervention in late effects." includes education while in hospital and/or at home.

Question 22 (p12)
Are there other objectives that should be included?
NCWNZ would suggest the following:

Education for children while still in hospital.

Siblings of affected children require special reassurance and possible examination to discount the likelihood of them being subject to cancer also.

Caregivers of children suffering from cancer also need greater support and possibly rehabilitation.

Question 23 (p13)
From your perspective, which of these objectives are the most important?
NCWNZ regards the objectives to be of equal importance.

Question 24 (p13)

Which actions do you think would be most effective in meeting the objectives you consider most important?
It will be necessary to develop strategies based on the provisions of the Health and Disability Act and Human Rights legislation to ensure that patients who have had cancer are not discriminated against, either in the workplace or in educational institutions.

NCWNZ members note that it is all very well to develop these materials and screening tools, but delivery with a greater than average degree of sensitivity may prove to be the more difficult challenge. As we have found in the delivery of mental health services, one programme is not suitable for all.

In developing vocational plans there needs to be an awareness of differing recovery rates (physical, psychological, social). In developing such plans consideration also needs to be given to ensuring that the jobs suggested are meaningful.

Funding for support services and palliative care and the use of effective multidisciplinary teams complemented by voluntary agencies will continue to be important especially when employed in a comprehensive "late effects" programme.

There must also be adequate funding for service providers so that they have opportunities for on-going training to be able to implement new treatments and services.

Guidelines need to be developed for District Health Boards and service providers to assist in the implementation of vocational and educational programmes.

Question 25 (p13)
Which organisations do you think should be actively involved in meeting these objectives?

- Ministry of Health
- Medical Schools and Associations
- Cancer Society/Canteen
- Maori Women's Welfare League
- Marae groups and other community organisations including ethnic groups
- Cancer Control Trust
- District Health Boards -- Social Services, Occupational Therapists, Psychiatrists, etc
- Health education providers to provide high quality training
- Hospitals
- Primary care givers e.g. GPs
- Funding Agencies so that we keep abreast of staffing issues, i.e. recruiting training, retention.
- Ministry of Education
- Ministry of Labour
- Human Rights Commissioners
- Look Good/Feel Better rather similar again
- Paediatric oncologists
- Inland Revenue Department (IRD)
- Work and Income New Zealand (WINZ)
- Citizens' Advice Bureau and Community Law offices
- Employer's Federation
- Disabilities Organisations
- Churches and other religious groups
- Unions

Appropriate information should be sent through to IRD, WINZ, employer's federations and associations and unions to discuss at their annual meetings.

Question 26 (p13)
Other comments?
When there is no longer a possible cure, treatment to prolong life should be carefully evaluated, with the patient/client being given all the options, in terms that are easily understood. Pain relief should be a priority and the patient should not be given false hopes, by offering expensive treatment, such as chemotherapy or radiation, when it is unlikely to give improved quality of life or prolong life. Where treatment is no longer effective a patient's right to refuse further treatment should be respected.

Financial support of individual and family members may need to include looking at the inadequacy of sickness benefits, and to assist with stress and travel needs. Insurance issues that can have a major impact on life, e.g. mortgage accessibility, may also need to be addressed.

Goal 5: To improve the planning, co-ordination and integration of activities and services to control cancer.

Question 27 (p14)
Do you consider the proposed objectives are likely to lead to effective action to achieve this goal?
Yes, but as has been stated there are shortages of specialist staff and other areas where staffing needs are either marginal or barely meeting demand. A change of employment attitude needs to happen. In the past there has been a vocational approach to staff undertaking various occupations. Nowadays, especially with the numbers of staff declining and equipment aging, stress levels are rising to the extent that for a time increases in pay level were seen as the answer to retain staff. This may have contributed to a hardening of attitudes to the extent that their roles are now seen as just another job.

Dealing with cancer patients is often made even more difficult as many cases have, like serious cardiac conditions, the potential for serious upheaval for patients, family, friends knowing that in many cases death is probable either in the shorter or longer term. This too can cause greater distress to the medical profession and carers. It is vital that realistic salaries, work conditions and staff support be developed and maintained to keep the experienced staff that we do have. NCWNZ urges the government to implement a programme to train and retain new staff.

While we would like to see a seamless service provided for patients who require palliative care, no matter where they live, we need to be realistic in terms of our previous comment.

Question 28 (p14)
Are there other objectives that should be included?
Respondents believed that there is a need for clear feedback channels for users and their families.

Question 29 (p14)
From your perspective, which of these objectives are the most important?
Respondents felt that the objectives were of equal importance. They made the following observations:

If objective 1, to “Develop a co-ordinated national cancer workforce strategy.” and objective 3, to ”Establish an integrated programme of supportive care and rehabilitation with defined leadership.” are not carried out and resourced properly then objective 2, to “Ensure that a seamless service is provided for patients with cancer who require palliative care, no matter where they live.” is not possible as the resources, especially in terms of staff will not be available, co-ordinated or otherwise.

In discussing lack of co-ordination reference was made to inflexibility of services, and inappropriate care. We would not like to see the practice of seeing people passed out of the hospital system too early as often happens in other areas, e.g. maternity, mental health, post surgery. This is very definitely a symptom of money before people and not just at the hospital level either.

Question 30 (p15)
Which actions do you think would be most effective in meeting the objectives you consider most important?
Our members made the following comments:

Better medical manpower planning and funding on a national basis with all District Health Boards contributing funds, not just for tertiary centres.

Funding on national basis not just tertiary centres.

Increase involvement of Maori and Pacific Island Health Professionals, regional Palliative Care network.

Forecasting needs for oncologists and radiotherapists to promote follow-up treatment within a reasonable time to ensure control of the disease.

Implement a strategy for workforce development. Regional palliative care networks to provide specialist support for population that they serve.

Guidelines developed and used by all stakeholders.

Question 31 (p15)
Which organisations do you think should be actively involved in meeting these objectives?

As for Goal 2 - Q13
- Ministry of Health
- District Health Boards and their staff
- Cancer Society
- Specialty medical groups all of which deal with malignancy and provide care
- National Hospice Society
- All health training establishments
- Palliative care providers
- Educational institutes
- Maori Health Professionals
- Pacific Island Health Professionals
- Other ethnic groups

Question 32 (p15)
Other comments?
Despite the reference by Moore (1995) that support and rehabilitation services have traditionally been mono-cultural, NCWNZ members would disagree, having seen people given treatment and support in many areas of New Zealand. If a few people have missed out, we would presume that it has been personal fear, ignorance or reluctance to access support or treatment from health services, rather than neglect by health providers.

Adequate manpower planning and distribution needs addressing. This means links with training centres and funding for those departments involved in specific training.

Care needs to be taken to ensure administration costs do not become excessive and reduce funding for care services. Full use needs to be made of modern communication technology.

Goal 6: To improve the planning, co-ordination and integration of cancer research, evaluation, monitoring and surveillance.

Question 33 (p16)
Do you consider the proposed objectives are likely to lead to effective action to achieve this goal?
Yes, but research should not only be the analysis of registry data and overseas studies.

Quality biomedical and clinical research is still necessary and can continue only if serious long term funding is available. Researchers we have at present are struggling and if we are not careful may have to go offshore. Consequently there is no point in trying to encourage undergraduates to consider a career in cancer research. A significant proportion of their time is spent trying to secure funds rather than doing research. We also support the need for well-constructed epidemiological and longitudinal studies.

High quality clinical databases can be invaluable to evaluate research, for clinical audits and managing services. A further but less widely recognised application is that of helping patients, together with their practitioners, to make informed decisions about their clinical management. An example of such an application is the use of breast cancer database in Finland (British Medical Journal, 2003; 326:29).

Question 34 (p16)
Are there other objectives that should be included?

No.

Question 35 (p16)
From your perspective, which of these objectives are the most important?
Members believe both objectives are equally important
Question 36 (p17)
Which actions do you think would be most effective in meeting the objectives you consider most important?
NCWNZ would suggest the following:

Provision of adequate funding of biomedical, epidemiological and longitudinal studies.

Accurate diagnosis. All information should be recorded and forwarded to a National Register. This should be relatively straight forward using today's technology.

Improve the Cancer Registry to manage collection, assessment and reporting of data.

Improve the quality and accuracy and consistency of ethnicity data.

Develop systems for ensuring accuracy and quality of data.

Develop performance indicators.

Adequate funding for National Cancer Register - Health Information Division of Ministry of Health together with quality monitoring and review.

Encourage joint venture research with the Health Research Council.

Promote value of ethically approved clinical trials.

Question 37 (p17)
Which organisations do you think should be actively involved in meeting these objectives?
- All District Health Boards, Independent research laboratories and others involved with diagnosis and treatment.
- NZ Cancer Registry
- Ministry of Health, Health Information Service
- Health Research Council
- Iwi

Question 38 (p17)
Other comments?
As a start, 'Investigating the social and behavioural factors that discourage people from seeking treatment, and psychosocial support…' should be able to be readily and easily compared and contrasted with research on other aspects of life that we do have information for. This should be done by social scientists to determine why people are discouraged.

Funding for specific Maori health problems could possibly come from relevant iwi funding in conjunction with Health Research Council funds. Some iwi have received considerable grants/funding and the incidence can be specific to particular iwi.

It may be worthwhile reviewing the Privacy Act as it appears that it has been interpreted in such a way that it has resulted in the collapse of a number of national registers of disease which makes prediction of needed treatment resources hard to assess. NCWNZ supports appropriate data be collected. Guidelines on what constitutes ethnicity are also needed. Data collection should be NHI (National Health Index?) number linked. Personal information needs to be safeguarded and only used for the purpose for which it was gathered.

Question 39 (p18)
Please write any additional comments you wish to make about the discussion document below.

Some NCWNZ members felt that the Submission booklet was written in such a way that it was very difficult to disagree with some questions (i.e. the questions were not open).

Many of the strategies appeared to be very idealistic and without adequate funding may remain so. So many of the strategies are relying on people changing their way of living (e.g. smoking, drinking and sex habits) and despite time, effort and money being put into education of the negative effects of these habits it is still not easy to get people to change.

Some contributors felt that the usual constraints on funding will continue to limit services and accessibility and therefore maintain only that which we have now.

NCWNZ thank the Ministry of Health for this opportunity to comment on what is a complex field. We support the approach that is being taken and look forward to seeing the final report.

Beryl Anderson
National President

Catherine Gurnsey
Convener, Health Standing Committee