CAN Australia submission to the Senate Inquiry into Cancer Services

BACKGROUND

The Cancer Alliance Network (CAN Australia) is a national network of consumer groups set up with the assistance of the Clinical Oncological Society of Australia (COSA) and the National Cancer Control Initiative (NCCI). CAN's member groups have included nationally organised tumour specific groups like the Breast Cancer Network of Australia (BCNA) and the Support and Advocacy Committee of the Prostate Cancer Foundation of Australia (PCFA) as well as several comprehensive state networks of cancer groups which are now terming themselves Cancer Voices in recognition of the pioneering group in NSW and similar groups in the UK and New Zealand. Some support groups are organised regionally, and these are welcomed into the network in their own right. Individual consumers may also join. We formally launched the network on World Cancer Day, 4 February 2003 in Sydney Town Hall, and currently maintain a small office with voluntary effort in Canberra. Our views attempt to represent those of our member groups who in turn represent tens of thousands of cancer consumers across Australia.

CAN identifies and supports a range of consumer representatives on various government and NGO committees formed to enhance cancer services are identified, referred and supported through our networks. This includes representation on the advisory board of the NCCI, the Cancer Council of Australia (TCCA) and on some of the Government's own committees like the Cancer Strategies Group of the National Health Priorities Action Council. We participated extensively in the processes which developed the Australian Government's National Service Improvement Framework (NSIF) for Cancer Services as a model for frameworks to address priority needs in all the National Health Priority Areas. CAN has also collaborated with NCCI and State Cancer Councils in the delivery of seminars on improvement of psychosocial care for cancer patients and their families. There is also constructive engagement with consumers in cancer screening processes as we are involved as representatives on the Australian Screening Advisory Committee, extending our focus beyond just cancer treatment services. As a result we have things to contribute in relation to Breastscreen accreditation issues, the bowel cancer screening implementation pilot projects and enhancements to the cervical screening program.

In addition, CAN has lent its support to formation of national alliances of consumers in other tumour specific areas such as lung cancer and brain tumours, and is seeking to facilitate the organisation of networks of consumers suffering the effects of colo-rectal cancers. We need to distinguish here the essential difference between community or public health interest in cancer (largely about prevention and well catered for by NGO's like the Cancer Councils and Leukemia Foundations) with the role of consumer organisations which are established to voice the concerns of people who experience cancer directly either as patients themselves or as carers and family members of such patients. The NGO's mentioned above often purport to speak on behalf of such consumers but in our experience they often do not accurately reflect our concerns, and that is why hundreds of cancer consumer groups have sprung up around the country. This is not to decry the excellent work done by NGO's in raising public awareness about cancer prevention, raising funds for fundamental cancer research and even on occasion providing limited support for consumer group activity. We are struggling to find effective ways of co-ordinating our sometimes disparate views. but believe that we as consumers need to control our own destiny

THE RATIONALE FOR CONSUMER INVOLVEMENT

The Australian Government is in a position to take a leadership role in consumer involvement in the development of services across the cancer continuum. To this end we applaud the recent initiative which has provided up to $2m over four years to support and maintain cancer support groups at the national and hopefully local levels. We would hope that any organisations it supports or consumer forums it conducts with these funds will advance the organised consumer group input to cancer care and not duplicate work that has already been done in the setting up of networks like ours.

However, as this funding has been introduced with minimal consultation with consumer groups, it fails to recognize the fierce desire of many consumer groups to be free to organise themselves in their own way, without interference from well meaning government and NGO health professionals and bureaucrats. The support needed is broader than providing funding to CAN Australia and other such groups. It is about how cancer consumer perspectives together with community values are incorporated within cancer service planning. Consumers need to be consulted with and supported in influencing:

- Definition of the problems of cancer service co-ordination and cancer control
- Prioritising solutions and action

We are pleased to have a representative role on committees considering aspects of improvement of cancer services and control of the disease, but issues of education and support for the broader consumer community and the need for multiple strategies to research and assess the social impact of cancer services also need to be addressed.

IMPACT OF CHANGES IN CANCER SURVIVAL OUTCOMES

We would also like to note that according to the NCCI, more than half of patients diagnosed with cancer are now alive more than seven years after diagnosis. This change in the outcome of cancer care in Australia requires a redefinition of the impact of cancer from the consumer perspective, and introduces such issues as:

- Chronicity and living with side effects of treatment
- Fertility preservation/Early menopause
- Pain and fatigue
- Rehabilitation
- Cancer care in the community
- Entry points to palliative care

These issues for consumers are not sufficiently reflected in the current emphases of government cancer programs and services nor those of NGO’s at the national level.

This submission is put forward to ensure that consumers are constructively engaged in any consideration of cancer services reform in Australia, and is presented against the Inquiry’s Terms of Reference.

CAN SUBMISSION TO SENATE INQUIRY

TOR (A): THE DELIVERY OF SERVICES AND OPTIONS FOR TREATMENT FOR PERSONS DIAGNOSED WITH CANCER:

Having experienced cancer care from a variety of providers in a variety of locales, consumers involved with CAN believe that services are unacceptably fragmented and too highly focused on treatment processes rather than patient or consumer outcomes. They do not live up to the various governmental definitions of cancer control and therefore could do with considerable realignment. The consumer perspective on the continuum of cancer services is that there is a greater complexity to cancer treatment than seems to be understood or acknowledged by many cancer service providers.

A(i) the efficacy of a multi-disciplinary approach to cancer treatment,

The ‘Optimising Cancer Care in Australia’ (OCCA) report (2003) recognised the issues of fragmented services and promoted multi-disciplinary care as a way of ensuring timely and appropriate access to services. In particular, co-ordination of service between surgery, medical oncology services and radiation oncology/therapy services is required, as is the integration of allied health services needed to support the main treatment modalities. Once these multi-disciplinary teams are engaged with a particular patient, it is essential that they co-ordinate their efforts and communicate effectively with each other as well as with the consumer and their carers. There is considerable anecdotal evidence that those who are lucky enough to get access to such co-ordinated multi-disciplinary care have better overall health outcomes, both in terms of quality and duration of life, and more formal studies are confirming these views.

The current governmental approach to cancer services signals a narrow clinical and epidemiological view of what cancer services are. From a consumer perspective it would be extremely relevant to see much more major qualitative research funded. Qualitative research that follows a large enough sample of people with cancer from diagnosis to survivorship or death, so that generalisable information becomes available that can shape specific recommendations for research and cancer service delivery. If there are questions about appropriate research methodologies then research into research strategies needs to be funded as well.

People diagnosed with cancer and their carers are convinced that a clear roadmap should be provided at the time of diagnosis to what should happen next in a treatment plan, who should be providing care at each stage and what can be expected as a result of treatment and follow up, together with what supportive care is available in or through the network of care providers. At the moment co-ordination of care is often left to the oncologist who first diagnoses a condition, but he or she often has little time and usually little training in how to do it. Supportive care in the case of cancer is a much broader issue than just plugging into the odd clinician in an acute care setting to fix a narrowly defined problem. The support needed has emotional, social, psychological and even spiritual dimensions. It may be covered by the wider implementation of the recently produced psycho-social guidelines for the treatment of adults with cancer, but this implementation needs to be properly resourced and evaluated, and a broader range of health professionals than just doctors and nurses needs to be co-ordinated into providing appropriate care.

CAN SUBMISSION TO SENATE INQUIRY

A(ii) the role and desirability of a case manager/case co-ordinator to assist patients and/or their primary care givers,

The designation of case managers to help co-ordinate care in various settings has become fashionable and there is emerging evidence to show that it does produce better overall outcomes for patients. However it is essential that the person providing such support has appropriate skills, and the task is not just dumped on the person who seems handiest at the time, like the breast care nurse for breast cancer sufferers, or the ward clerk in a radiation therapy setting. A preferred term for some is the title “System Navigator”. The need for such help will vary greatly between patients based on their knowledge of the health system and their condition, as well as their emotional, psychological and physical wellbeing. The person charged with this responsibility needs to have appropriate professional background and training to perform task effectively. We note the emergence of the specialist oncology social worker, and further development of this speciality, whereby needs assessments of new patients are undertaken by them as a matter of course, and support provided on a needs basis including referrals to other clinicians as required. Access to treatment services should never rest with just one clinician or class of clinicians. Used properly, the care co-ordinator role can empower users of cancer services. Employed carelessly, it will add another layer of complexity and expense to an already stretched health system. It requires a cultural change amongst care providers as much as a new class of health professionals.

A(iii) differing models and best practice for addressing psycho/social factors in patient care,

There is no “one size fits all” model in our experience, but little evidence that best practice is recognized let alone promulgated. The network of breast care nurses which has been resourced over the past decade or so is probably quite appropriate for addressing some of the psycho-social needs of women with breast cancer, but doesn’t necessarily translate to men with prostate cancer, whose needs might better be met by facilitated self help groups or whatever. And there will be variable needs within each specific disease group. Whichever model is chosen, there needs to be support for its effective implementation. It’s not enough just to publish psycho-social guidelines; governments must engage clinician and consumer groups to participate in their promulgation.

A(iv) differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians

It is unclear at present how much disadvantage is suffered by those affected by cancer just because of where they happen to live, and/or their socio-economic status. Better data, research and analysis is needed before we can be fully informed about this, but there is a definite impact on access to services and subsequent mortality rates of those impacted by various cancers. In our view it is essential that rural and remote consumers have affordable treatment options comparable with their city cousins, and don’t decline most efficacious treatment (e.g. being able to opt for radiation therapy instead of mastectomy to avoid social disruption and the cost of having to temporarily relocate to access radiation therapy)..

One of the findings of a review of the various jurisdictional schemes for supporting patient accommodation and travel to access treatment (conducted in the context of improving access to radiation oncology services) found a need for greater consistency between jurisdictions and better promulgation of information about accommodation and travel support to ensure that optimal treatment decisions are affordable and acceptable to consumers.

The issues facing Indigenous people in accessing cancer services were well canvassed in a seminar sponsored by TCCA in Darwin last year. The barriers here are cultural as well as economic and the tyranny of distance doesn't help either. Greater empowerment of indigenous health workers and better resourced screening and early detection processes should help here, but some of the cultural inhibitions to seeking treatment far away from home are much harder to address This problem is going to get bigger as indigenous life expectancies improve, as detected rates of cancer in indigenous communities will inevitably rise as they achieve an older age profile.

A(v) current barriers to the implementation of best practice in the above fields;
As noted above, the recognition of best practice is difficult, and this seems to be a precursor to promulgating it more widely. A soon to be published scoping study of an accreditation framework for cancer services may help to change this situation. An appropriate accreditation process based on continuous quality improvement, if implemented, would set standards and provide for regular peer review against them, allowing for quality of services to b ranked say on a scale from 1 (little achievement) to 2 (some achievement) to 3 (moderate achievement) to 4 (extensive achievement) to 5 (outstanding achievement of best practice). Mechanisms exist to partner those service providers at the upper end of the scale with those at the lower end to ensure promulgation of best practice. Under the medical model culture which prevails in almost all cancer services, clinicians will only rally adapt their practices on the basis of input from their peers. The current inter-relationships between various cancer services would seem to be deficient in promoting this approach, although the moves in several states towards consolidate cancer streams or even cancer institutes may make a difference. The purported introduction of Cancer Australia may also facilitate sharing across jurisdictions if handled properly. There are models for such inter-jurisdictional co-operation already in operation such as the Radiation Oncology Reform Implementation Committee, and the National Blood Authority, which need to be carefully assessed before Cancer Australia's governance is settled. However, to be really effective, it is our belief that the culture of the medical model of treatment needs to be influenced in the earliest parts of clinical training, by ensuring that all doctors see themselves as (essential) parts of multidisciplinary teams which are accountable to the community they serve through appropriate quality frameworks which involve some degree of accountability to the administrators of the health services they work in as well as to individual consumers and peers. This is generally not the case at present.

That being said, we would like to acknowledge the workforce shortfalls which impact on the capacity of clinicians to provide adequate let alone best practice services. Whilst this is a general problem across the entire healthcare workforce, it is most evident in some of the cancer services, with oncology nurses often having to fund their own access to specialist training through fundraising activities, whist those already on the oncology wards are tempted into the emerging community based care co-ordination roles for which they are not always appropriately trained, but which offer more attractive working conditions. Similarly, radiation therapists are in shortage because their role is not always respected and they can earn double the salary in overseas postings where they are more appreciated. Psychologists brought in to provide psycho-social support are often unversed in the realities of cancer and provide little real benefit to patients or their families, leading to constant turnover because of more rewarding opportunities for their skills elsewhere. And the underutilized oncology social workers have been all but invisible in the past few years, perhaps because they have the capacity to challenge the supremacy of the medial model of cancer care and the top dog oncologists who benefit most from it. The solutions to these workforce problems are not simple. They involve better working conditions for all staff, role redefinition, culture change and better fundamental training and support..

Another barrier is the concentration of resources in the acute sector of the health system when we will increasingly need support for care in the community setting. This will probably involve an enhanced role for GPs, one which they currently feel ill equipped to handle because of limited access to basic training in cancer treatment and excessive demands on their time from routine lower level services provided to healthier consumers.

TOR(B): HOW LESS CONVENTIONAL AND COMPLEMENTARY CANCER TREATMENTS CAN BE ASSESSED AND JUDGED,

‘To ensure access to quality cancer care, quality must be monitored across the entire continuum of care, including early detection, diagnosis, treatment, follow-up, and palliation. (Malin, *et al* 2000:706)

We would extend this call for adherence to quality standards in cancer care to complementary and less conventional therapies.

B(i) the extent to which less conventional and complementary treatments are researched, or are supported by research,

CAN is aware that many consumers turn to less conventional treatments where options offered by mainstream services offer less than ideal outcomes. Often these services have little evidence of efficacy, although the practitioners can be more empathetic to consumers than their counterparts in the mainstream and thus fill consumers with sometimes unwarranted confidence in the treatments they provide. As a consequence, consumers often fork out relatively large amounts of money for unproven treatments not subsidised by the public health system, and even where there is no verifiable therapeutic benefit, they may feel better because of the placebo effect and the relatively better communication they establish with their alternative practitioners. Unfortunately alternative and complementary practitioners are less regulated than mainstream providers, and are not required to put in effort to justify their treatments. A research funding approach by the NHMRC that focussed on debunking ineffective alternative treatments for cancer as well as trying to find ones that worked might be one mechanism to address this. It would need to have more emphasis on the sociological aspects of therapeutic practice rather than its current emphasis on the fundamental science. CAN strongly supports the establishment of clinical trials register with government funding encompassing not just mainstream pharmaceutical interventions but a range of other therapies.

An example of consumer motivation in this area is a small group in Canberra which has set itself the task of raising $500,000 in a year to fund research into unconventional therapies for asbestos related cancers. It looks like achieving the goal, but is having some difficulty in ensuring that the research it funds will benefit the consumers whose lives they are trying to affect because of horrendous experiences recently deceased consumers have had in following conventional treatments.

B(ii) the efficacy of common but less conventional approaches either as primary treatments or as adjuvant/complementary therapies

There is no doubt that some people receive benefit form unconventional cancer therapies such as the approaches promoted by the Gawler Foundation. This could be because cancer is a multi-dimensional disease, as noted above, and these therapies deal better with the emotional, psychological and spiritual elements of a person's condition. However, it is not clear to us whether this is enough to warrant diversion of scarce health service resources to the subsidization of such treatments. Only by the detailed study of the less common interventions will assessments be able to be made of the extent to which the placebo effect is operating. For every person who commits personal resources to alternative treatments and obtains benefit, there are probably several who miss out on real benefits from more conventional therapy as a result of pursuing an impossible cure. CAN would urge governments not to have closed minds on alternative and adjunct therapies and to recognise that some consumers are less risk averse than others and will want to pursue radical therapies which are possibly curative but have little likelihood of effective outcomes rather than conventional therapies with known incremental benefits. For this reason it would be useful to look at ways of providing accelerated access (such as provisional Msdicare Benefit Schedule or PBS listings) to potentially useful conventional and complementary therapies.

B(iii) the legitimate role of government in the field of less conventional cancer treatment

CAN believes that government should have a role in disproving ineffective therapies as well as in establishing effective ones. To this end it should be sponsoring more research and clinical trials focusing on such approaches, and in establishing more effective regulation of alternative and complementary therapy practitioners.

FUTURE STRATEGIC DIRECTIONS

There appears to be considerable pressure for the current NCCI to be subsumed in some sort of national cancer organisation termed Cancer Australia, with an as yet indeterminate structure, maybe as part of a broader network of National Institutes for Health as in the USA, or as a distinct entity along the lines of the UK model. Before supporting such a development, consumers would need to see a clear rationale for what would necessarily be a much more extensive and expensive process. On the one hand, we acknowledge the benefit of consolidating resources to avoid duplication of effort and dilution of the talent pool, but on the other we recognize that there is a danger that ambitious people vying for key leadership positions in such an umbrella organization could inhibit the momentum for integrated and optimized care by pushing their own approaches to the exclusion of others.

What benefits a nationally funded network under the banner Cancer Australia might bring to consumers is not immediately obvious to us, but it is clear that the Australian Government has taken a relatively very low outlay approach to date, and to continue funding such a significant health problem at such a low level is unlikely to optimise cancer care and prevention in this country. It is essential that advisory arrangements at the national level have broader than just jurisdictional input. Whatever organisational model is adopted, we believe that there needs to be a tripartite approach to its governance involving bureaucrats and the clinician and consumer communities. Rather than committing massive resources to a new organisational structure like a Cancer Australia and defunding numerous smaller initiatives, it might be better to recognize and support those visionary and courageous leaders in cancer care who can be shown to be making a difference. This would certainly involve additional funding, but perhaps involving a merger of NGOs like the Australian Cancer Network and COSA with government instrumentalities like the Cancer Strategies Group within NHPAC. A revamped Australian Council on Safety and Quality in Healthcare will also have an impact on the delivery of safe and efficacious cancer services.

Work sponsored by the Australian Government (through agencies like the NCCI and NBCC) has generally been of value in the better co-ordination of cancer services over the past decade. It has demonstrated a commitment to improving consumer health outcomes despite minimal allocation of new resources to address a growing challenge caused by the increased prevalence of cancer largely brought about by Australia’s ageing population. Co-ordination of services in the various jurisdictions is patchy, but there seem to be moves in the right direction in most states. The private sector provision of cancer services also needs attention because some people have no option but to use these services (e.g. for timely access to radiation therapy) and the inequitable cost burden it produces for such consumers is unacceptable in a country which boasts about its universal health care system.

CAN believes that the current conceptualisation of the problems that these agencies have addressed has limited the capacity of government to have maximal impact on the delivery of cancer services in Australia. Any future initiatives must provide for more usable power to influence and control the integration of clinical service delivery and to set strategic directions, and this will require additional resources over and above those which have been provided to it to date. Whatever role Cancer Australia plays in the future, it must continue to work collaboratively with consumers to ensure our needs are understood and met in the best way possible.

CAN Australia ***18 March 2005***