cancer voices nsw

the voice of people
affected by cancer

# Consumer Perspective

on the

# Productivity Commission

position paper on

# Australia's Health Workforce

**Cancer Voices NSW — 8 November 2005**

## About Cancer Voices

*Cancer Voices NSW is the peak coalition for 83 cancer support and advocacy groups in NSW. It provides a voice for the 4,000 members of these groups to improve the cancer journey for people affected by cancer.*

*We are interested in the areas of prevention, diagnosis, information, treatment, research, support and care. Cancer Voices NSW works in collaboration with and provides consumer representatives for the boards and committees of key cancer and health organisations in NSW and beyond, such as the Cancer Institute NSW and the Cancer Council NSW.*

*Similar groups to Cancer Voices NSW are being established in all Australian states and territories. The impetus to form a national cancer consumer body has recently remerged from meetings held nationally among cancer consumer groups.*

*Cancer Voices NSW is also associated with the national Consumers' Health Forum of Australia whose involvement as primary consumer representative in health workforce reform we advocate in this paper.*

> *"…health professionals must learn to treat the patient, not just the disease…"*
>
> Professor Barrie Cassileth, Chief of Integrative Medicine Service, Memorial Sloan-Kettering Cancer Centre, New York delivering the keynote address at *Complementary Therapies in Cancer Care: Informing Choice,* Garvan Institute of Medical Research, Sydney, 21 October 2005, organised by the Cancer Council NSW and Cancer Voices NSW.

## Contents

## 1. Summary

The Commission is correct in observing that "health care consumers are becoming more discerning about the type of services they require". Consumers are also concerned about the health system itself. They perceive the health system as, too often, alienating, cumbersome, inflexible and bedevilled by reactionary self-interest. The needs for health workplace redesign are incontrovertible. However, we lack confidence in the capacity of the health bureaucracies and professional groups to move towards a patient-focused approach at anything more than glacial speed. Cancer Voices NSW (CVN) maintains that, by having consumer groups participating on key decision-making bodies, pressure for more rapid system improvement can be applied.

While noting that the Position Paper proposes only cautious and **gradual** change to excessively bureaucratic structures, CVN nevertheless agrees with the its main thrust. In particular CVN supports Proposal 3.1 that CoAG should endorse the National Health Workforce Strategic Framework (NHWSF). This is appropriate since the CoAG Terms of Reference for the study require the Commission itself to "have regard to the NHWSF…" Moreover, it is by reference to the NHWSF framework that CVN draws attention to shortcomings in the paper.

The NHWSF places a strong emphasis on **consumers as stakeholders**. To paraphrase and condense, the Framework, having emerged from consultation with… **consumers and carers**, … sets out to provide rules which will allow **all stakeholders** to engage in applying them. Policy planning should be population and **consumer** focused and will be most effective when undertaken collaboratively by **all stakeholders**. This will require cohesion among **stakeholders**, including **consumers, carers**… and will require **stakeholder** commitment to the framework's vision, principles and strategies (our emphases).

The Paper does not come to terms with these NHWSF precepts. The approach to consumer engagement in agencies of health workforce restructuring are obscure and inconsistent: the latter especially when one looks at variations across the various components of the Position Paper. We will explore these inconsistencies in detail. Suffice to say for the moment that consumers appear in the text as stakeholders sometimes, but at other key points seem to be totally overlooked. We suggest an added proposal that specifically deals consumers in. The Consumers' Health Forum should be the primary base for consumer engagement in workplace reform.

Consumers, we suggest, are not mere occasional or intermittent stakeholders. Consumers have a strong interest in system equity, effectiveness and efficiency. In various ways consumers are the ultimate funders of the **inputs** to the health system. At the other extreme, consumers are the stakeholders most concerned with the **outcomes** of the system – it can even be a life or death concern. From a consumer standpoint the Position Paper focuses too heavily on process and outputs, thereby contributing, albeit unintentionally, to perpetuation of the current overemphasis on the means rather than the ends of health service delivery.

Cancer consumers have as keen an experience of the shortcomings of the present system as any – an ageing, declining workforce; shortfalls in prevention and screening (radiographers, radiologists, pathologists…); shortage of professional services especially in remoter areas; specialist silos and reluctance to engage in multidisciplinary teamwork; inadequate socio-oncological and palliative care; lack of consultation in diagnosis, prognosis and treatment…. The CVN *Charter of Cancer Consumer Values* sets out principles applying to cancer care (Appendix 1), many of which, we suggest, have application across the wider health system.

Consumers are increasingly commenting with their behaviours on the perceived shortcomings (outcomes) of the present health system. The research evidence, though scarce, of a high rate of growth in the use of complementary and alternative medicines (CAMs) should be grounds for professional concern, especially as the studies show that fewer and fewer patients are making their health professionals aware of this behaviour. There should not only be research into the use, merits and demerits of CAMs, but some measure of regulation or accreditation. We think that the Position Paper might have considered this rapidly emerging issue.

The Commission has, therefore, set the scope of its inquiry too narrowly. The paper begins with the traditional disciplines that are already (too) firmly entrenched, then moves on to those immediately adjacent disciplines that are competing for new space on the medical stage. Meanwhile, the emerging trends are overlooked.

To conclude, it is consumers who matter most. It is consumers who are the primary stakeholders for whom the system exists and who must therefore be prominently engaged in system reform. Of all health stakeholders, consumers will press hardest for change. They are largely overlooked in the Position Paper.

## 2. The National Health Workforce Strategic Framework (NHWSF)

We have noted in our Summary that the CoAG Terms of Reference enjoin the Committee to "… have regard to the National Health Workforce Strategic Framework and other relevant bodies of research."

The NHWS framework is centred on seven guiding *Principles.* These principles contain multiple allusions to consumers: consumers are mentioned as stakeholders in collaboration with all other stakeholders in policy development and planning (Principle 7); as people and communities with needs (Principle 2); and as requiring health workforce policy and planning that is "consumer focused" (Principle 6). Principle 4 refers to "health outcomes" while Principle 5 again refers to "health outcomes" as well as to "service needs".

Elsewhere in the Framework document the AHMC says: "Empowered consumers will demand to know more about the treatments proposed for them, their effectiveness and the track record of the practitioners involved in their diagnosis, testing and treatment. Track record knowledge can also be expected to extend to the facility or setting in which the service and care is being provided. All this will affect the management of knowledge and the development of procedures, protocols and guidelines for effective safe care. Again this will mean that the workforce imperative is for up to the minute knowledge and therefore an education and training environment that effectively imparts, and properly updates, this information."[1] Each requirement flows from the one before it.

Again: "The [Guiding] principles **interlink** (our emphasis) and have been developed to focus on the key action areas that will be essential to the delivery of the vision. These can be summarised as…. Recognising that health workforce policy involves **all stakeholders** (our emphasis) working collaboratively with a commitment to the vision, principles and strategies outlines in this framework (see principle 7)."[2]

And again: "The strategic action required here is essentially recognition of this principle [Principle 7]. And more importantly, its **constant and consistent** (our emphasis) application to the development and implementation of Australian workforce policy:

- Develop national and jurisdictional plans to action this framework.
- Establish the monitoring, evaluation and reporting processes to support the framework [including annual progress reporting to Australian Health Ministers].
- Develop inclusive, consultative processes around the development of health workforce policy and planning that engages **all stakeholders** (our emphasis).
- Promote discussion and awareness of health workforce issues and strategic action among **stakeholders and the general community** (our emphasis)."[3]

We do not think that the Committee has adequately followed this strategic direction. In the next section we examine the extent to which the strategic action pointed to in the NHWSF is carried through in a "constant and consistent" manner into the Proposals in the Position Paper.

## 3. Inconsistent Treatment of Consumers as Stakeholders

The Committee has not, in our view, fully appreciated the deep concern of consumers (and their carers and supporting volunteers) for health workplace system reform. While CVN is in broad agreement with the main thrust of the Committee's proposals, we consider that it is too much a matter of exchanging one bureaucratic process for another and, therefore, of pursuing long overdue reform of archaic structures and practices at too slow a pace.

These weakness, we suggest, are related to a failure to develop an overview of the health system in terms of its required outcomes, and therefore give full consideration to those system stakeholders — consumers — who are most deeply concerned about those outcomes. This failure most obviously leads on to inconsistencies across the Committee's proposals, as shown in tabular form below:

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[1] National Health Workforce Strategic Framework, April 2004, page 11.

[2] Ibid, page 14.

[3] Ibid, page 23.

## Health Consumer Involvement as System Stakeholders

### Analysis of Productivity Commission Key Draft Proposals

| Agency/Council | Draft Proposal | Executive Summary | Main Report |
|---|---|---|---|
| **Advisory Health Workforce Improvement Agency** | ***Proposal 4.1 — No***<br>Stakeholders groups detailed but consumers specific-ally **not** included | ***Page xxxv — Yes***<br>"balanced member-ship…as well as **consumer representation**." | ***Page 53 — No***<br>"health, education and finance knowledge and experience"<br>**No consumers** |
| **Advisory Health Workforce Education and Training Council** | ***Proposal 5.2 — ?***<br>Stakeholders groups not detailed | ***Page xl — ?***<br>"expertise of the various stakeholders …[and] a balanced membership".<br>Implies **no consumer involvement** | ***Page 76 — Yes***<br>"…all professional areas…and consumers"<br>**Consumers involved** |
| **National Accreditation Agency** | ***Proposal 6.1 —?***<br>Stakeholders groups not detailed | ***Page xlv — ?***<br>" have broad based membership, drawing on additional expertise as required".<br>Implies **no consumer involvement** | ***Page 100 — Yes?***<br>"broadly agrees" with Victorian Government proposal to include "professions…and consumers."<br>**Consumers involved?** |
| **State Based Registration Boards** | ***Proposal 7.1 — ?***<br>Stakeholders groups not detailed | ***Page xlvii — ?***<br>New governance where existing arrangements hinder change.<br>**Consumers not mentioned**. | ***Page 115 — Yes***<br>"As consumer protection is the main aim…boards should include consumer representation."<br>**Consumers involved** |
| **Independent Funding Review Body** | ***Proposal 8.1 — ?***<br>Stakeholders groups not detailed | ***Page li — ?***<br>*"broadly based and independent".*<br>**Consumers not mentioned.** | ***Page 134 — ?***<br>"more transparent process…a broadly based and independent body…."<br>**Consumers not mentioned.** |
| **Strategic Workforce Advisory Secretariat** | ***Proposal 9.1 — No***<br>Consumers not included. | ***Page liv — No***<br>Professionals, yes, but **consumers not included**. | ***Page 156 — Part?***<br>Specialist working parties **<u>might</u> include consumers.** |

Depending upon how deeply a decision-maker were to venture down through the layers of the Position Paper, so she would encounter inconsistent, even conflicting proposals about consumer involvement in workforce reform. Consumers are not mentioned in any of the Committee's Proposals proper. In proposal 4.1 other stakeholders are detailed but consumers are conspicuously omitted — although they are specifically mentioned in the Summary yet overlooked again in the body of the Paper.

Consumer involvement is alluded to in the main text relating to Proposals 5.2, 6.1, and 7.1, but nowhere in the Proposals themselves or in the Summary. Consumers are not mentioned at all in relation to Proposal 8.1, although there is an allusion in the main text to a more transparent and broadly based body.

There is no suggestion of a place for consumers on the Proposal 9.1, Strategic Workforce Advisory Secretariat — notwithstanding the reference to "consumer focus" in Principle 6 of the NHWSF — although there is a passing suggestion in the main text that consumers might be involved in some of the secretariat's working parties. In this regard we commend Policy Principle 5 of the *Consumer Policy Principles for the Health Workforce*[4] of the Consumer' Health Forum of Australia.

We suggest that, at the very least, these internal inconsistencies in the Policy paper should be attended to. We would prefer, however, to see Chapter 3 contain an additional (sub) section which specifically picks up the NHWSF references to consumers as stakeholders and includes a blanket Proposal that consumers should be included on all boards, councils and bodies recommended in the Position Paper.

To add weight to these proposals, we now go on to argue in Section 4, below, that consumers are, not just one stakeholder group among many, but would more appropriately be seen as first among equals.

## 4. Consumers are the Primary Stakeholders

The Commission points out, quite correctly, that the health workforce is heavily shaped by government intervention. Not surprisingly, Government commitment to financing inputs is itself, along with an archaic medical guild system, a major contributor, through an over focus on process and organisation, to the bureaucratisation of the health workforce.

The Figure 1 on page xix of the Paper suggests that the funding sources for Australian Health Care are as shown in the table below. This apparently confirms the primacy of Government intervention in the system. Patients/consumers appear to contribute a mere 20%.

**Sources of Funding for Health Care**

| Funding Source | Percentage |
|---|---|
| Australian Government | 46% |
| State/Territory Governments | 22% |
| Patient Contributions | 20% |
| Private Health Insurers | 7% |
| Other | 5% |

We suggest, however, that this is not the whole picture. Platitudinous though it might seem — yet it remains the case — the vast majority of government health care government funding is obtained from primary taxpayers who are, in turn, health care consumers. Only the most disadvantaged Australians are not current consumers of Australian health care. The ultimate funders of the inputs to the health system are very largely its consumers, whether it be via income or GST taxes, direct contribution, insurance premiums, or even donations. Consumers are therefore vitally concerned with the performance of the health system, and its workforce. This concern reflects itself in the high level of attention given to the health system in political agendas, throughout the Parliamentary cycle but especially at election times. To put it another way, "Health resources are scarce and governments have obligations to their 'shareholders' (taxpayers) to ensure that tax revenues are spent effectively"[5].

Though often overlooked, consumer contribution to health care funding is by no means the end of the story. Consumers are deeply and even vulnerably engaged with the health workforce itself, as patients. It is most often on this basis, rather than any other, that some consideration might be given, on occasions, to involving

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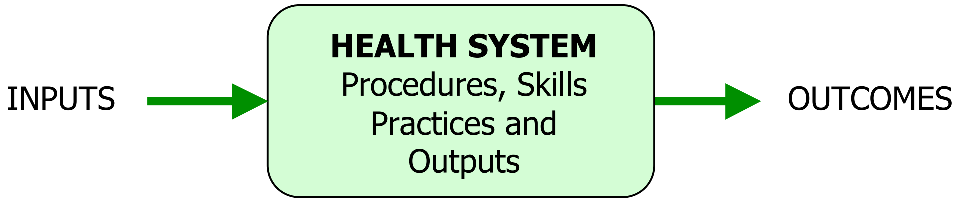
[4] Appendix 2

[5] Access Economics, *Indigenous Health Workforce Needs,* a report for the AMA, July 2004, page i.

consumers as stakeholders in health care policy and planning processes. Certainly, this consideration seems to underlie the NHWSF and, to the extent that consumers are taken into account, the Commission's Policy Paper.



The figure above borrows from, but schematises, the useful SCRGSP diagram shown on page 32 of the Commission's Position Paper. Consumer contributions provide inputs to the system. Consumers are also among the stakeholders enmeshed within the system itself.

But consumers are also the stakeholders most concerned with the **outcomes** of the system — for obvious health reasons. From a consumer standpoint the Position Paper focuses too heavily on the central box — process and outputs — and thereby helps to perpetuate, albeit unintentionally, the current overemphasis on the means rather than ends (outputs) of health service delivery. Similarly, although it is to be preferred, we do not think that the Australian Health Ministers have gone far enough in recognising an appropriate status for consumers in drawing up the NHWSF.

Given then that consumers are involved from inputs, through system performance to outcomes, it follows that consumers should be concerned and involved **as much as any other stakeholder** with improving the performance of the health system and its workforce. And if consumers are involved as major stakeholders in workforce reform, that reform will occur more rapidly that it otherwise would.

For these reasons we recommend that Consumers' Health Forum of Australia (CHFA) should be the major peak consumer body invited to supply people for all the bodies proposed in the Position Paper. It would be reasonable to expect that, in selecting such people and in accord with past practice, the CHFA would take into account the kinds of qualifications, skills and governance experience appropriate to the body in question.

## 5. Present Consumer Dissatisfaction and the Future System

It is frequently said[6] that "consumer needs and expectations are changing" and are demanding more of the health care system. Yet there is little research into what those expectations might be. Similarly there is little research into consumer behaviours, into what directions they may be heading and how they might consequently impact in the future on the structure of the health system and its workforce. In short, there appears to be an unshakeable lack of curiosity about consumers/patients on the part of most policy makers and of many practitioners.

There are, of course, occasional but honourable exceptions. For example, the NHMRC Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer (2003), which propose deeper engagement with the emotional needs of patients, full provision of information, integrated care and genuine cross-discipline teamwork, including:

- The provision of information
- Integration of quality-of-life issues into the care of patients with cancer
- Minimising the social and psychological impact of cancer on a patient and their family
- Strategies for the identification and management of patients experiencing significant emotional distress.

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[6] For example, in both the NHWSF paper and the Productivity Commission Position Paper. Yet the Productivity Position Paper list of References appears to contain only one —by Rankin et al — that surveys health care consumers.

Yet, as cancer consumers ourselves we observe that many specialist practitioners are slow to take up and act on these guidelines. For this reason, among others, we have developed the CVN Charter of Cancer Consumer Values[7]. We seek to encourage practitioners to treat the patient as well as the disease.

While there are references in the early part of Chapter 5 of the Policy paper to "adjustment of education and training arrangements to the changing requirements of those receiving… health care services"[8] the remainder of the chapter moves its focus to inputs and process in "hard" areas — clinical, specialist, nursing… shortfalls — but devotes little discussion to outputs and patients. Not surprisingly, therefore, the recommendations that emerge from the chapter are, at best, ambiguous about consumer/stakeholder involvement in the training advisory council.[9]

We do not, however, wish to appear to be arguing against the improvements the paper proposes to the current system. As sufferers of one form of chronic and life threatening disease, we only too well aware of the shortfalls in access to "traditional" radiographers, radiologists, pathologists, surgeons, oncologists, colonoscopists, anaesthetists, specialist nurses, psychologists, social workers and the like. We seek a broader approach and a more consumer oriented solution.

## 5.1 Informing Consumer Choice

We support the Breast Cancer Network Australia in saying[10] "…The requirement of consumers to have knowledge and information about their healthcare treatments and the options available to them continues to grow. It is no longer considered acceptable to make decisions about patient management without providing the patient and their family with the opportunity to be involved in that decision-making process. The new approach to clinician/consumer communication places an increasing burden on clinicians to be effective communicators…and accreditation and credentialing criteria should include measures of the effectiveness of clinicians' skills and other skills required for the delivery of best-practice care."

The consumer communication dimension of performance and accreditation receives no attention in Chapter 7 of the Policy Paper and we believe this shortcoming should be redressed. Again, we suggest a clear and consistent recommendation for the involvement of consumers in the National Accreditation Agency.

## 5.2 Multi-disciplinary Teams & Care Coordinators

Appropriate care requires an approach in which health professionals **together** consider all relevant treatment options and develop an individual treatment plan for each patient. It is known as "multidisciplinary care". It has been highlighted in both national and state cancer plans as a key aspect to improve cancer care: "Evidence has shown that multidisciplinary care can reduce mortality and improve quality of life for patients with cancer…. While there is general agreement in the medical community about the benefits of multidisciplinary care, there are considerable challenges in making it a reality.[11]"

"In addition to the physical impact of their disease, women with breast cancer are dealing with emotional, psychological and practical day-to-day issues.[11]" Multidisciplinary teams should therefore include psychologists and social workers. Among the "new" professions, we recommend inclusion of "Coordinators of Care". We support the BCNA is suggesting[12]: "Implementation of multidisciplinary care, while demonstrating better healthcare outcomes, leads to a need for greater coordination of clinical management and information exchange between patients, families and the range of clinicians involved in care…. The evolution of the breast care nurse role has been effective in filling this need…. This model may also flow through to other areas of healthcare."

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[7] Appendix 1.

[8] Page 55, also pages 56, 60 and 62.

[9] Page 76 versus pages 77 and xl.

[10] BCNA Submission to the Commission, pp. 5-6.

[11] Dr Helen Zorbas, Director of the National Breast Cancer Centre.

[12] BCNA Submission to the Commission, pp. 4-5.

We commend the Cancer Institute NSW initiative in making grants of up to $100,000 to cancer care centres that wish to establish multidisciplinary teams and recommend the model's wider application.

### 5.3 Complementary and Alternative Medicines (CAMs).

In some respects there is a state of affairs approaching a crisis of confidence in orthodox health care system. At the Garvan Institute of Medical Research in Sydney recently[13], Dr Alison Evans of the National Breast Cancer Centre reported on a very recent survey of 368 women with breast cancer which found that 90% used Complementary and Alternative Medicines, averaging 2.9 per patient. Only two-thirds of these consumers mentioned this to their health practitioner. Further analysis is yet to be done to identify the depth, or otherwise, of the discussions between patient and health practitioner on this CAMs usage. There is sufficient anecdotal evidence, however, to suggest that many consumers find their health practitioners reluctant or even averse to discussing CAMs, and generally ill informed on the merits, demerits or potential dangers of mixing CAMs with conventional treatments.

"These interventions do not cure cancer. Any claims that complementary modalities cure cancer are completely bogus. They do, however, provide important relief of symptoms, and they are highly valued for that…. But because few oncologists are familiar with complementary and alternative therapies, they need data to help distinguish between those that are inappropriate or dangerous, versus those that are safe and helpful…. What is desperately needed is objective information and solid data…. We wanted to make sure that consumers and physicians had a safe, reliable place to go for data-based therapies as well as information about their usefulness or lack of benefit.[14]"

The best estimate of the use of CAMs in Australian society is that it approximates $2 billion per annum. From this nearly $200 million is collected in GST. CAMs is therapy that consumers are prepared to pay for themselves, without pharmaceutical benefits assistance, and without the benefit of dealing with accredited practitioners.

CAMs therefore represents an issue which penetrates decision making about health care research, education and training, and accreditation registration. Yet there is a lack of funding for research and evidence-based decision-making, apart from the Report of the Expert Committee commissioned by the Department of Health and Ageing[15] whose recommendations have been largely been left unacted upon.

Sadly there is no evidence of CAMs receiving attention in the Productivity Commission Position Paper and no mention of CAMs in the list of References. We agree with the BCNA is commending Recommendation 28 of the Expert Committee on CAMs relating to registration of CAMs practitioners. We also suggest reference to Recommendations 22-29 of the Report of the Senate Cancer Enquiry, 2005.

In summary, the Commission has, we believe, set the scope of its inquiry too narrowly. The Position Paper as a whole takes as its starting point the orthodox disciplines that are already (too) firmly and narrowly entrenched, then edges outwards to those immediately adjacent disciplines that are competing for space on the medical stage. Meanwhile, the emerging trends are overlooked. This applies particularly in the case of Complementary and Alternative Therapies.

Consumer needs and expectations of the health care system and patient behaviours receive too little examination. Patients are treated as passive receivers of professional health care rather than engaged participants with a deep concern for good outcomes. Consumers are too seldom included as members of those bodies recommended to implement the proposals of the Position Paper, and when consumers are alluded to their positioning and roles are obscurely stated.

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[13] *Complementary Therapies in Cancer Care: Informing Choice,* 21 October 2005, organised by the Cancer Council NSW and Cancer Voices NSW.

[14] Dr. Barrie Cassileth, Chief of the Integrative Medicine Service at Memorial Sloan-Kettering Cancer Centre, New York at www.mskcc.org/mskcc/html/17902.cfm

[15] Complementary Medicines in the Australian Health System, 2003

## 6. Recommendations

We suggest the Commission recognise more appropriately that the current health system is supply driven rather than demand or patient need driven[16] and focuses too heavily on processes rather than consumer-related outcomes.

We support the Productivity Committee's Proposal 3.1 that the Council of Australian Governments should endorse the National Health Workforce Strategic Framework.

We consider that the Commission itself in its final Report should have closer regard to the National Health Workforce Strategic Framework, especially Principle 7.

We recommend that Productivity Commission review its proposals for stakeholder engagement in health workforce reform, recognising that health systems consumers are the primary stakeholders in the health system and that, of all stakeholders, consumers are most anxious for rapid and comprehensive improvement.

We commend to the Commission the Consumers' Health Forum of Australia "Consumers Policy Principles for Health Workforce" of June 2004[17], in particular Principle 5, which states that "consumers must be equal partners in national health workforce planning".

We recommend that further attention be given in Chapters 5 and 6 to the expectations of consumers with chronic and life-threatening illnesses with reference to the NHMRC Clinical Practice Guidelines for the Psycho-Social Care of Adult Patients with Cancer.

Specifically, we recommend that the Productivity Commission revise its Position Paper so as to clearly and consistently propose consumer stakeholder membership of:

- The Advisory Health Workforce Improvement Agency;
- The Advisory Health Workforce Education and Training Council;
- The National Accreditation Agency;
- State Based Registration Boards; and
- The Strategic Workforce Advisory Secretariat (with its structure revised, as necessary).

We recommend that the Consumers' Health Forum should be the primary source of consumer engagement in health workforce reform and consequent health workforce agencies.

We suggest that the Commission adopt a wider view of what might constitute the potential health workforce and take cognisance of consumer expectations, dissatisfaction with current arrangements and increasing recourse to complementary and alternative therapies.

## 7. Some Relevant References

DHS (Department of Human Services, Victoria) — Consultation Paper, *Participation in Your Health System: Victorian Consumers, Carers and the Community Working Together with the Health Service and the Department of Human Services,* Melbourne 2005. (www.health.vic.gov.au/consumer/participate.pdf)

DHS (Department of Human Services, Victoria), *Key Performance Indicators, Participation in Your health Service System Carers and the Community Working Together with the Health Service and the Department of Human Services,* Melbourne 2005, especially pages 2 and 3. (www.health.vic.gov.au/consumers/participation_indicators.pdf)

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[16] See, for example, the submission to the Commission entitled *Health Workforce Reform*, by John Menadue AO.

[17] Appendix 2.

# Appendix 1

## CHARTER OF CANCER CONSUMER VALUES

**Cancer Voices seeks adoption by the "cancer world" within which we operate, of a set of principles which recognise and protect the value, dignity and voice of people affected by cancer.**

*This Statement is inspired by Articles VII and VIII in the Charter of Paris Against Cancer of 4 February 2000. International signatories, including consumers, were asked to take the principles home and turn them into practice. This Statement is our contribution toward that aim.*

*Many stakeholders influence the cancer journey, especially people who have experienced cancer. We recognise that these people are uniquely motivated to assist in decreasing the impact of the disease. We recognise the value of cancer "consumers" (as in consumers of cancer service and research outcomes) as active partners in the combined effort to reduce the impact of the disease, and will promote their participation by adopting the following principles:*

1. All people affected by cancer, or potentially affected by cancer, are entitled to information concerning the disease, including its origin and stage, the current treatment options available and their side effects, the latest medical research results (including access to clinical trials), the costs and availability of the various treatment options plus their location, together with current standards for detection and diagnosis.

2. All cancer patients are entitled to optimal care, medical or otherwise, irrespective of stage or type of disease.

3. Open and collaborative communication between the patient and the various members of their multidisciplinary health team is essential.

4. A commitment to total patient well-being includes not only the provision of optimal medical care but also to the provision of current information and psychosocial support.

5. The importance of quality of life is recognized, for *all* cancer patients and at all disease stages, from diagnosis to death, and in the development of new treatments, new medications and procedures and in patient care and support.

6. People affected by the disease will be encouraged to be informed, organised and influential, and will have a role in the decision making processes impacting on them and at all levels.

7. The professional health and scientific community
   - recognises the benefit of an informed and active consumer community
   - will facilitate consumer participation in the scientific process
   - will ensure comprehensive and balanced reporting of scientific and medical evidence
   - will promote scientific assessment of complementary and alternative therapies.

8. The medical, research, industry and policy communities will regard cancer consumer advocates as key strategic partners in all aspects of decision-making for prevention, detection, diagnosis, treatment, care, support and the direction of research.

# Appendix 2

**Consumers' Health Forum Of Australia**

## Consumers' Policy Principles for Health Workforce

## June 2004

**Policy Principle 1:** Consumers must be involved in setting standards, accreditation and re-accreditation of health professionals to ensure that the courses reflect community needs and produce professionals that are able to provide culturally appropriate care.

**Policy Principle 2:** Health professional courses should review entry standards and mechanisms to ensure that people from under-represented communities, such as people from culturally and linguistically diverse and Indigenous backgrounds, are not prevented from training as health professionals. Courses and professional registration bodies should review entry/eligibility criteria to ensure that appropriately qualified practitioners from overseas are not prevented from practising in Australia.

**Policy Principle 3:** All health professional associations should develop and implement a mandatory program of ongoing professional education for members.

**Policy Principle 4:** All health professionals and consumers should work collaboratively in devising community-based options for professional development.

**Policy Principle 5:** Consumers must be equal partners in national health workforce planning. Greater national focus is required to address nursing and allied health shortages and to improve coordination between the medical, nursing and allied health workforces.

**Policy Principle 6:** Consumers must be able to participate in any decision-making about the recognition of new health 'specialties'.

**Policy Principle 7:** The 'public interest' framework used by the Australian Competition and Consumer Commission for determining whether health professional education should be the subject of competitions should be supported. Greater consumer input to course development and implementation would increase the utility of, and community faith in, such education.

**Policy Principle 8:** All states and territories should pass mutual recognition legislation for all registered health professionals.

**Policy Principle 9:** Professional bodies should ensure appropriate mechanisms for dealing with unprofessional behaviour and misconduct to ensure quality health care to the community. Best protections are afforded when these professional body mechanisms operate in tandem with an independent government-funded health complaints body.