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Developing a Strategic Plan for Cancer Services in the ACT

A Discussion Paper

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Area Health Management Program

Discussion Paper

Developing a Strategic Plan for Cancer Services in the ACT

Issues in achieving healthcare reform at the regional level.

Project Officer

Kate Burns

March 1996

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Introduction

This paper has been written as a supporting document to the strategic plan that was developed through a consultative process over a number of months. The Commonwealth government sponsored the project under its Medicare Agreement New Initiatives funding through the Area Health Management Program.

The paper discusses the issues within two sections. The major part of the work was the analysis of needs of those living with cancer which comprises Part I. The second section explores descriptively the conceptual implications. Further analytical and conceptual work will be needed over the next few years.

Part I: Identification of needs

This section was undertaken using a participatory consultative model in conjunction with a literature discussion. The discussion at the end of each section provides some signposts for further community and professional exploration.

The theme throughout the project, and braided through this paper is patient participation and perception of care. For this reason the Care Continuum was used as a conceptual structure for examining the needs of those at risk of or diagnosed with cancer. While it enabled the usual approach concerning cancer control, through health promotion/prevention measures, to be acknowledged, the majority of time and effort was spent on the issues of cancer management

The reason for this is simple. The ACT together with Australia has a rapidly ageing population as a result of the baby boom generation maturing. This will create special pressures in the early decades of next century for the health sector in the way that it did for the education system in the post war decades. Cancer is already the number one cause of death and likely to remain so for the foreseeable future The preventive health measures currently known have only a limited impact on tumour control and the strategy of preventing cancer is therefore still of limited benefit.
Improvements in how patients diagnosed with cancer are managed is therefore the priority.

Part II: Implementing a Strategic Plan for Cancer Services at the regional level.

This section begins by providing an overview of the reform initiatives being undertaken at the national level those reforms by federal and state health ministers throughout Australia's healthcare system. This project is a small part of those reforms.

A discussion of the strategic and implementation process is provided as a prelude to the profile of the ACT cancer population and a description of current services .

The record of the joint working party discussions which led to the development of the Strategic Plan then follows. Implementing this plan requires commitment from a wide range of agencies, service providers and professional support staff, and leadership from a cancer expert advisory group. The context within which this group would operate is provided by an outline of the purchaser/provider funding model about to be implemented, and by an overview of the research, information and data needs including clinical audit that are a prerequisite to any sensible evaluations.

The literature is replete with concerns raised throughout the western world about the variability in cancer treatment due to a range of complex factors, but primarily because no single medical discipline provides overall leadership in cancer care. The complexity of the disease itself and of its treatment creates very special emotional pressures for patients and their families and friends. Its chronicity, its prognostic uncertainty and current treatment modalities all create very particular demands on the planning and resource management of both our health and community care systems. There are no simple, prescriptive answers. Neither is the enormity of the problem grasped in a quick read or even a range of elegant statistical profiles.

This project has attempted to bring together the experience of all those engaged in the task of cancer care and control within the ACT and to provide a strategic focus for where to go. This document is aimed to support the next stage, including the establishment of a cancer expert advisory group to provide the leadership for implementing the plan. The documentation recorded here is of necessity limited as the project engaged only one full-time person on the task. But the energy and commitment of all those involved, who are listed in Appendix A, and most particularly the Reference Group and those chairing the working parties informed the approach taken to the task.

This paper does not pretend to exhaustively examine the medical treatment issues of cancer management. Technical areas in both diagnostic and pharmaceutical support and workforce planning have been excluded almost in their entirety. However information in all areas is available elsewhere and the planning implications flowing from this discussion will of course require attention in other forums and settings. What this paper does offer is a fresh view of cancer management from a consumer perspective. The ACT is fortunate in already having membership within its local Oncology Services Consumer Group of some 45 - 50 people who provide a dynamism unique in the country. The complementary Oncology Services Network provides a regional forum across the three tiers of health service delivery that also provides the ACT with a highly accessible communication structure. These very real strengths combined with the resource of a federal policy oriented culture will enable this region to contribute to the emerging challenge of cancer care in the twenty first century.

While the limitations of this paper are born solely by the author, it has however been immeasurably enhanced by the efforts of the following. Drs Bruce Shadbolt, Doris Zonta and Paul Craft all read the final document in detail and made numerous suggestions which have been incorporated. The working papers on which this final report has been built had the invaluable comments of the following - Mr Peter Field, Mr Russell McGowen and Dr Geoff Caldwell, Ms Jenny Satrapa and Ms Cathy Smith together with Dr Ian Prosser, Ms Denise Montague, Mr David Rhodes, Ms Ilya Lovric, Ms Victoria Jones and Dr Elizabeth O'Leary. My colleagues in the Epidemiology Unit, Ms Carol Gilbert and Ms Norma Briscoe not only provided intellectual and emotional support but assistance in editing this report and ensured its 'delivery'.

The project has dealt in only a peripheral way with the needs of children with cancer, in part because paediatric oncology is not a sub-specialty in Canberra and children who receive treatment here are under the care of oncology physicians in Sydney. Children of parents diagnosed with cancer are recognised as having special needs which the Palliative Care Business Plan and the Bereavement Community Education Strategy are acknowledging in particular ways.

Part A: Identification of health needs of people diagnosed with cancer

Identification of need

The Australian Area Health Management Program

The Area Health Management Program (Schedule G) of the Medicare Agreement provided the framework for the development of an ACT Strategic Plan for Cancer Services. The contract with the Commonwealth entailed a dual strategy of exploring the application of a cancer services strategic planning model within an area health framework and developing an information strategy to engage the wider community in an understanding of the concepts.

The program aimed:

- to identify and demonstrate the essential elements of an effective area health management mechanism
- to promote the advantages of area health management and particular key elements on a national basis.

Five key objectives were nominated for the framework

Area Health Management Program Objectives

Identify health needs

Improve service links to ensure optimum continuity of care

Develop planning mechanisms that are cost-effective to health/service needs

Explore purchaser/provider split

Expand information and data systems.

Project methodology

After the initial objectives had been clarified[1] and a substantial literature search had been undertaken by the project officer, a Reference Group was established. It comprised sixteen community and consumer representatives, service providers from both the health and community agency sectors, epidemiologists and health administrators. The membership list is attached in Appendix A together with some background notes.

This group took as its approach a social health orientation to the examination of cancer care and control and employed the conceptual tool of the Care Continuum to examine issues of service need.

In its first meeting the Reference Group committed itself to the establishment of five working parties drawing on the full complement of some 47 representatives in the cancer service field within the ACT (see Appendix A for membership details).
The working parties established were as follows:

Reference committees				
Health promotion/ prevention	Diagnosis & early intervention	Treatment	Rehabilitation & extended care	Palliative care

Rationale of working parties

Representation had initially tried to achieve a balance of one third consumer, one third service providers, and one third policy/planning /research support. However the complexity of cancer care, and the range of service providers meant that it in fact the ratio was closer to one quarter consumer, one half service providers (thus enabling multidisciplinary representation) and one quarter professional support staff – epidemiologists and health administrators.

The working parties have been seen as the key to the interpretation and analysis of health needs. Their composition has enabled direct links across the primary, secondary, and tertiary sectors on all points of the care continuum.

None of the working parties attempted to undertake a formal needs analysis. However, the resource of the consumers enabled a variation on the community needs analysis model to be used:

- health issues in the cancer field had been broadly sketched in the national health goals and targets consultations and this material was summarised by the project officer in the first report – *Setting the Agenda* –for the membership.

- key informants drew on their professional experience, across the multidisciplinary settings;
- the group's knowledge of community services and programs and their experience enabled an informed judgement to be made of unmet need.

- literature searches undertaken by the project officer provided the material for draft Issues Papers used by some working parties actively as a resource for discussion;

- ongoing attempts were made to identify data needs with the aim of developing a framework for a cancer data and information system relevant to the recommendations. This included discussion of the research questions that still need to be asked.

Undertaking a formal needs analysis for cancer care/cancer management as the ensuing paper outlines will be a complex and large–scale task requiring not only much conceptual work at a multidisciplinary level, but also well designed studies using research questions informed by consumer surveys. Building such a knowledge base in Australia will take time and a shift in the professional paradigms that currently dominate the debate. Research into cancer treatment itself is already a major industry with many vested and competing elements. Consumer research interests will need support and leadership from within the public sector.

Effective planning mechanisms matching health needs and services cannot be developed until the data and information system (underpinned by a hospital–based cancer registry) is formally established. In particular, the cancer burden on hospital outpatient services, interstate service use and the extent of unmet need of those living with cancer (cancer survivors) in the community.

At present no cancer services outside South Australia have sufficient data to enable regional planning for cancer care and control to be done on any systematic basis.

The Reference Group when forming the five working parties decided that the groups could tackle the needs issues on their own terms given the constraints in resources and time, and what was for many a new model of practice. As a result, the working parties approached their tasks in a variety of ways, although interestingly they achieved a fairly comprehensive response across the cancer care continuum issues nominated by the debates in the Australia–wide context. Indeed the working party deliberations have highlighted a number of shortfalls in the current national discussions.

Format of each section

The outcomes against the goals established by the working parties for each point in the care continuum are presented. This is followed by an outline of the main issues considered by that working party together with a discussion of the relevant literature. The working party's recommendations follow with a final discussion of implications for the ACT based on the author's views.

Health Promotion Prevention

Under Health Promotion/Prevention:

The Australian Cancer Society published its national prevention policy in 1993 [2] and made the point that firstly the risk of most cancers increase with age. While risk factors vary for specific cancers four strategies have been nominated as contributing to cancer prevention:

- reduction of tobacco consumption
- reduction to sun exposure
- adoption of a prudent diet
- reduced alcohol intake

In conjunction with the National Heart Foundation, the state cancer councils have successfully run anti–smoking campaigns around Australia for over a decade. Prevalence of smoking in that time has fallen from 40% for men and 29% for women in 1983 to 29% and 24% now among women.[3] Australia leads the world in attempts to control skin cancer.[4] A number of community programs encouraging the use of protective hats and sunscreen together with changed attitudes to suntans and the discouraging of sunburn in children appears to be shifting attitudes.[5]

Chemoprevention is also emerging as a new discipline in oncology. The pharmaceutical Tamoxifen is currently being trialed as a phrophylactic against breast cancer and results will be available within a few years. Various antioxidants including aspirin and non–steroidal anti–inflammatory drugs are also being examined for the prevention of colonic cancer. While a range of vitamins is also being advanced no properly designed studies have yet been undertaken to determine their benefit in cancer prevention.[6]

*The NHMRC in a recently released Discussion Paper[7] noted there are many interpretations inherent in the use of the term health promotion but emphasise that they are bound by one major factor: that is, **the primary focus of the activity is population health.** Population health, in turn, is characterised by four main principles, namely*

- *a focus on prevention;*
- *an understanding of the causes and determinants of illness and other conditions;*
- *evidence-based practice;*
- *community participation in decisions which impact on their health.*

The NHMR emphasised a point which is applicable to this discussion, namely that the contribution of one to one clinical work is a significant health promotion activity especially when delivered in conjunction with the above principles

Goal: To define and explore the concept of health literacy and cancer care and make recommendations back to the main reference group.

Outcome: The group met seven times from February to June 1995. This working party began by acknowledging the considerable achievements of cancer control in Australia which have included identifying risk factors for cancer and specific cancer prevention efforts. ACT health goals and targets[8] had already spelled out a range of cancer prevention strategies to improve mortality and morbidity goals and the group therefore felt encouraged to focus on other aspects of health promotion.

Members considered that their energies would be better spent in examining health literacy and its relevance to cancer care and control. A draft Issues paper was developed which forms the basis of the discussion of the literature that follows. A model of communication along the cancer care continuum is being developed and will be submitted for publication by the working party in an appropriate professional journal.

The recommendations made by the group formed the basis of their contribution to the strategic and implementation plans

Health promotion and prevention key issues

Health promotion and prevention key issues

Health literacy across the care continuum

Determining literacy

Information giving

Communication

Autonomy

Implementation of the ACT Cancer Health Goals & Targets

Health literacy

Health literacy is defined as *the ability to gain access to, understand, and use information in ways which promote and maintain good health. "(Nutbeam Report.)*

The draft Issues Paper explored the relationship between literacy and health, examined in detail health literacy and cancer care along the care continuum and sketched some conceptual frameworks for further exploration. The group's thinking was influenced by two research areas:

- the biomedical research field which has examined information giving , patient/doctor relationship, and patient perceptions and cancer care; and
- the public health literature which focuses on broad concepts of social health and examines such enabling factors as knowledge, attitudes and beliefs within the social and economic environment.

The Nutbeam Report[9] introduced the concept of health literacy and health skills as factors determining how people use information, obtain advice about health or treatment and gain access health services, or learn to use the health care system more effectively. The authors were at pains to illustrate the complexity of the underlying causes of ill health and represent the social and environmental determinants of health.

The indicators nominated in the report for measuring life skills (that is resilience and coping) were self esteem, access to assistance in coping with loss and grief, and opportunities to develop problem–solving skills.

The relationship between literacy and health

A lack of literacy affects people's health. Studies have confirmed a direct link between literacy and health, limiting an individual's personal, social and cultural development. While studies in non–industrialised countries confirm that illiteracy is independently linked with poor health status it was only recently that the same correlation was found in a U.S. study[10] The study found the relationship between reading level and physical health was statistically significant after adjusting for confounding sociodemographic variables. Highly significant associations between education level and six key risk factors for disease – knowledge about health, cigarette smoking, hypertension, serum cholesterol, body mass index, and height have also been found[11] while studies undertaken at the University of Arizona College of Medicine in Tucson found low literacy and high health costs were correlated.

Winkleby et al exploring education level and risk of disease posited that higher education protects against disease by facilitating the acquisition of positive social, psychological and economic skills and/or by providing insulation from adverse influences *"Beneficial assets that may accrue with education include positive values and attitudes about health, higher self–esteem, effective coping skills, access to preventive health services, and entry into a social milieu where the adoption or continuation of positive health behaviour is reinforced."* The recent report on health status in the ACT confirms this picture.[12]

That a lack of literacy indirectly affects people by limiting their access to health information has lead to various responses in a number of countries. In Canada, the Public Health Association launched a national demonstration project on literacy and health to increase awareness about illiteracy among health care workers.[13]

In the U.S. the National Cancer Institute began a new initiative called the Low Literacy Program which investigated a number of approaches for reaching this population with cancer information including audiovisual material and rewriting its publications from the current 10th grade level to a 3rd grade level. Two studies gave impetus to these moves: A 1992 study of the American Cancer Society's patient education material found a high level of reading ability was required[14]. and an analysis of 2,000 health care publications found almost all were written in the same language used in medial school and incomprehensible to the average American.[15] A pilot health education program in South Africa has also raised the issue of visual illiteracy.[16] It found that the view that all visual material has educational value was still prevalent (as it probably is in Australia). The study identified several problems including the lack of a clearly identified target group, use of the same material for different age or ethnic populations (often motivated by a focus on cost savings) and wide variation in the visual literacy skills of the target group.

A study of knowledge and beliefs about cancer in a socioeconomically disadvantaged United States population[17] whose average level of education was nine years found age, education and race were variables for a number of misconceptions and knowledge deficits. Functional literacy was not assessed.

Information giving

No study to date has explored the concept of health literacy along the cancer care continuum; changing needs, changing attitudes and competency over time.
Despite its importance to the delivery of health care, the study of this topic is in its infancy. Research is descriptive, comprising observational studies and experimental interventions and links to theory are tenuous or non existent.

Beliefs about and attitudes to cancer in the recent US study found misconceptions were rife. mongst a socioeconomically disadvantaged population: 33% believed surgery caused cancer to spread, 66% thought a bump or a bruise could cause cancer, and 33% stated that cigarette smoking did not cause cancer. By contrast in the ACT it was found that only 6% considered bumps or bruises caused cancer, 86% considered smoking to be a major cause of cancer and 79% were aware of genetic links.

Views on unconventional therapies in three US studies[18] [19] [20]almost a decade apart showed that significant numbers of people in the US continue to consider non traditional medicines could help cancer. A study currently being undertaken within the ACT will examine this question under Australian conditions but the evidence to date from the attitudes and beliefs study suggests that the majority of people in Canberra do not consider such practices to offer curative treatment. Older people have been found to be less involved in cancer detection behaviours and to seek care at a more advanced stage of their disease[21] [22] Belief in cancer myths, recall of the Cancer Society's seven warning signals and recognition of the symptoms of disease all showed statistically significant relationships with education and race[23]

Various studies have examined the special needs of women in regard to their use of screening programs for cancer of the cervix, approaches to information giving for both breast and cervical screening programs and alternate approaches to written information.[24] [25] [26] [27] [28] [29] Dhamija studying the correlates of knowledge found that younger women have better awareness and knowledge about cervical cancer and related information; literacy status for education and exposure to family planning was influential in creating awareness about cervical cancer, earlier episodes of gynaecological problems and treatment seeking behaviour lead to higher awareness. The ACT study found younger women nominated text books and journals as one of their three main sources of information on cancer.

Cross cultural research demonstrates that a persons sociocultural system influences the development of specific modes of perceiving, thinking, problem solving and relating to others. A study[30] examining the relationship between the culturally specific health–illness beliefs, values and practices of the Hmong and their level of literacy and traditional teacher learning styles, confirmed the importance of language and community in oral cultures, and the relationship between language, learning and communal life. The implications for Australian multi–cultural cancer care has still to be explored.

A number of studies in the past few years have examined patients' knowledge of their disease and specifically whether they understood they had a cancer diagnosis. No standard instrument has yet been developed and all studies are essentially descriptive. The major finding of this exploration is that wide cultural variation exists. In the US., Canada, France most people (up to 80%) are aware of their diagnosis [31 32 33]. However, in Italy and Spain the figures are almost reversed, with more than half of samples surveyed not understanding the nature of their diagnosis [34 35]Sources of information also vary widely and over the past decade or so appear to have shifted considerably in English speaking countries . Earlier studies showed high dependency on physician input for basic understanding of cancer knowledge [36 37 38 39 40]but later studies demonstrate the emergence of new sources[41 42 43 44] The three main sources of knowledge in the ACT study show similar variability, with relatives or friends and professionals other than specialists now becoming significant information sources. The study had one striking finding in the stratified sample as a whole – 22% used textbooks as a major source of information; although the figure for individuals diagnosed with cancer was much lower (8%).[45]

A number of studies have examined the patient/physician relationship and its effect on treatment options for cancer patients. Informed consent still appears to be an issue. A 1980 U.S.study[46] examining the readability of surgical consent forms found the readability was approximately equivalent to that of material intended for undergraduates or graduate students. The forms clearly did not comply with the goal of obtaining informed consent. Olver[47] in Australia in 1995 found the story appears little changed: of 100 patients given written information and a consent form only 34 understood the purpose of the form and only one considered it a major source of information.

Eidinger et al who examined the question of patient understanding of treatment goals, found no significant correlation between education level and knowledge of treatment goals[48]. Hughes [49] found that neither the amount of information nor the manner of presentation affect choice of treatment by patients with breast cancer. The amount of information patients received prior to their clinic visit was the most significant determining factor. Given the findings in the psychological literature regarding anxiety and recall have identified the import of these emotions on cognitive processing, this outcome is not surprising.

Patient participation in treatment decision making was first explored by Cassileth in 1989 followed by a number of other studies.[50 51 52 53] These studies have found that doctors tend to overestimate their patient's understanding of their illness, that patients may be reluctant to make initial therapeutic decisions, but wish to participate in ongoing evaluation of therapy, which are frequently gender based that education level, assertiveness and negotiating skills, all contribute to the context in which mutual participation in decision making takes place. Various studies have discussed strategies for increasing patient participation in decision making.[54 55 56 57 58]
No studies on health literacy and cancer rehabilitation appear to have been done. However the Rehabilitation & Extended Care working party took particular note of the major Canadian Cancer Society study[59] undertaken in the early nineties which found that people living with cancer nominated wide ranging information needs which were

frequently poorly met. Information needs were classified as medical, practical and emotional. This issue is explored in the next section of the paper.

Research is also limited at the palliative care end of the care continuum. Full disclosure of diagnosis to cancer patients is a significant determinant in the type of medical care such patients receive and the extent to which their emotional needs are met.[60, 61]

While many studies have stressed the link between information giving and communication, acknowledging that patient signals of their palliation needs may be varied and subtle, discussions in the literature have also raised the relevance of cultural factors in palliative care[62, 63, 64] The function of denial as a coping measure is currently being explored in a Sydney study but Mackillop in Canada found that the issue of effective communication was still a critical factor.

Communication

While acknowledging that a body of theory is yet to be constructed that would enable an assured debate, the working party was keen to explore some theory that might inform the relationship between health literacy and cancer care.
Three approaches were briefly examined:

1. Patient Provider Interaction

The social psychology field has explored the concept of communication in a variety of ways. Health professionals themselves influence behaviour. [65] Disagreement on the nature of the health problem, appropriate treatment and expected outcomes is common.[66, 67, 68, 69] A lack of awareness of patient attitudes, concerns, and perspectives,[70, 71, 72, 73] all have a negative effect on patient satisfaction and compliance and resolution of problems. Providers often lack adequate interviewing skills, overestimate the amount of information they provide, underestimate the amount of information patients want[74, 75, 76], and have difficulty detecting and resolving compliance problems.[77, 78] Patients in return are often reluctant to express their desires or request information.[79, 80]

Examining what primary behaviours enhance communication between patient and provider, Joos and Hickman developed four perspectives from a wide ranging literature search. These take account of cognitive and information processing, the quality of interpersonal interaction, differences between patient and provider perspectives and social influence.

2. Literacy learning

Education theory was the second field the working party saw as being of value. The late Ms Jenny Satrapa, herself an educationalist, and a consumer representative on the working party, suggested the literacy learning model[81] as a useful conceptual model. The idea that a cancer diagnosis is a learning task was a view confirmed by all the consumer representatives and the social work team. Cambourne's model describes a learning process that begins with immersion in the subject matter, and takes account of people's expectations, acknowledging individual differences in learning pace and readiness and their need to receive 'feedback' from exchanges with others more knowledgeable.

3. *Communication in Cancer Care: the Canberra model*
   The Canberra model as described by the group sees that the communication context has three overlapping but separate elements: cognitive processes, psychological dynamics, and societal/environmental forces which together interact on the dyiad of the patient/health professional and carer/family group.
   Optimal cancer care takes account of such communication along all aspects of the care continuum.

Autonomy

One of the important ways individuals can sustain autonomy in the health setting is through self care and self help. These concepts together with the need for social support were part of the health skills identified within health literacy in the Nutbeam Report.

Health maintenance and active participation in professional care were elements discussed in various working parties of the project. The Nutbeam report made special mention of the changing role of the acute hospital and the implications of the early discharge practices for carers in particular:

"as the population ages, and increased emphasis is being placed on the home care conditions which may previously have been managed in hospital or other institutions, carers are being expected to take increasing responsibility for many self care activities."[82]

The issue of social support has also been widely acknowledged in the literature as one of the prerequisites for health. A sense of belonging is identified as important for social wellbeing. Kumpusalo[83] defines social support as the interaction between people in which they give and receive mental, emotional, informational, operational and material support. A number of levels are encompassed within this concept: immediate personal relationships, neighbourhood and community support, services provided by voluntary agencies, and the services and policies of governments.

Nutbeam et al described Kumpusalo's categories as follows:

- *Material support e.g. money, goods, medicine*
- *Operational support, e.g. services community infrastructure;*
- *Informational support, e.g. advice, advocacy, guidance;*
- *Emotional support e.g. empathy, love, encouragement.*
- *Mental support e.g. common ideology, beliefs, philosophies. "*[84]

It is still unclear whether social support in itself prevents illness or whether it acts as a buffer against stressful situations reducing their impact. For those with established health problems adequate support is important for day to day coping for both themselves and their carers. It was noted that not all social support is good. The quality of the relationship can limit social support, for example, marital problems, families giving wrong or limited advice, and judgemental health services.[85]

Three groups with special needs were identified:

- *people experiencing transitional or major life events* such as people diagnosed with cancer
- *people who find themselves without established or diminishing social support networks, for example,* as a result of employment changes or relocation, or as a result of discrimination or stigma
- *people who have few resources available to them within their immediate social network,* for example, in Canberra this would include some professional and executive people.

Health Promotion/Prevention working party recommendations

Health Promotion/Prevention working party recommendations

Literacy:

1. Develop strategies that acknowledge and address lack of literacy as a barrier to health information.

2. Ensure all cancer material is reviewed to comply with current standards of education accessibility.

Information giving:

3. Develop minimum standards for information–giving along the care continuum.

4. Ensure information is provided and programs developed and evaluated that offer all patients the opportunity to actively participate in informed treatment decision making in regard to
   - their referral pathway
   - their disease process
   - mastering the terminology of the language
   - assessing treatment options
   - obtaining support services.
   - evaluating benefits of alternative services.

Communication:

5. Programs continue to be developed that assist patients to orient themselves to their health system in general and the hospital system in particular e.g. the "guided tour" – how it works, and seminars on how to manage it.

6. Health teams be encouraged to develop audit programs to evaluate their communication effectiveness.

7 Professional education programs be developed across the care continuum to ensure high quality communication skills, and knowledge of the appropriateness, timeliness and consistency of information is provided to cancer patients.

8 The development of clinical programs that use social psychology theory to enhance understanding of health behaviour e.g. theories of self efficacy, coping, learned helplessness, and social support.

9 The acknowledgment of the differing information needs of Carers, migrants, and Aboriginal and Torres St Islanders should be reflected in programs that include the characteristics of the above recommendations and each groups special needs.

Discussion

ACT Health and Community Care in changing its organisational role has been developing a population health focus. Public health practice in its emphasis on providing education to individuals, empowerment of individuals and communities, and the development of strategies to bring about changes in social and physical environments has much to offer clinical practice in cancer care. The current project, housed in the Population Health Division illustrates many of those public/population health principles. A consultative model of practice which drew on a genuine partnership of all concerned was the underlying value orientation.

The health promotion/prevention working party by selecting health literacy was able to highlight an important value that those living with cancer are seeking in cancer services planning and provision; namely a respectful partnership in decision making in regard to individual treatment choices and in the decisions the community may make around resource allocation.

The late Jenny Satrapa who had been a pivotal intellectual force in this working group had in the early discussions expressed a keen interest to translate our ideas into a working model to be introduced to a joint working party planning session. Her skills as an educationalist along with her own experience as a person living with cancer preceded by that of her father's death from cancer, enabled her to make a rich contribution as an observer, and a social scientist of the health system. Her values were those of the egalitarian – and she had a sophisticated understanding of the democratic significance of concepts such as access and equity. To her mind, health literacy encompasses ensuring that the individual has the self esteem, personal confidence and skills to negotiate treatment options with the physician, as well as the opportunity to contribute to such groups as the Oncology Services Consumer Group (OSCG) which can provide the vehicle to translate ideas into action. As an example, the reference group created a broadly focused Patient Information Kit, that draws on the excellent material already available to provide those travelling through the system with some early signposts. Not least of these is the acknowledgment by the mere act of creating the document of expressed care from others who themselves are sharing the experience of a cancer diagnosis.

The tasks therefore that have been identified in the Implementation Plan need this understanding – this values orientation which may in turn require self examination from us all.

- How can we demonstrate that those whose mother tongue is not English are obtaining and exercising the same treatment choice as the rest of us? Is the Aboriginal community both here and in the surrounding region sufficiently comfortable with the health system that they access it in time to obtain optimal treatment choice on their terms?
- How can we develop education programs for those for whom cure is not possible, so that they and their families have an up to date understanding of cancer pain and its control? How to draw to the attention of the community the distinction indeed between pain and suffering and what we can do to assist – simply, good humouredly – to alleviate suffering.

Individual empowerment can be developed by simple measures. Patients who understand their diagnosis, prognosis, treatment aims and goals have higher levels of autonomy and capacity for choosing treatment options. Self management so described in the literature is well illustrated by the introduction of the CAD pump that enables patients to undertake a complex drug regime without hospitalisation. In the ACT maintaining the supply is the only problem – that those in decision making positions understand that money invested " here" saves many dollars "there". Joint family managed palliative care can immeasurably improve the quality of life of individuals. It sometimes requires an investment in a range of health literacy tasks to enable the family group to organise both their time, their employment and financial affairs, and obtain the confidence to undertake the task. Language and cultural beliefs however, as well as age and gender influence people's perception of their capacity to undertake effective self management.

It is the same story when social support is examined as part of the psycho–social needs of people living with cancer. In a developing city such as Canberra, despite its accoutrements of middle class comfort, the lack for many of the extended family places an enormous psychological burden on the individual. Social support becomes a very real necessity to provide emotional sustenance. What kind, for whom, when and how are research questions we need to explore and answer. Is there a connection between survival rate /quality of life and types/level of social support? The answer is we don't know.

There are culture specific questions that need answering such as the attitudes of ACT migrant men and women to population screening for cervical and breast together with clinical screening for colon and prostate.

Finally, in terms of professional roles/education we need to start integrating health literacy concepts fully into clinical practice – beyond effective information giving.

Diagnosis and Early Intervention Working Party

Goal: Develop an Issues Paper on Diagnosis and Early Intervention in Cancer Care, Patient Perspectives..

Outcome: The working party met on six occasions between March and June 1995 and began their task with a brainstorm of the issues considered important. This group was fortunate in having a high level of consumer representation which ensured the focus was patient centred. Their questions set the consumer framework (later confirmed in an NHMRC Breast Cancer background paper) for exploring the issues of effective diagnosis and early intervention in the management of cancer within the ACT. The project officer who had also undertaken a literature search drafted a discussion paper. Their comments and review formed the basis of the Issues Paper then presented to the Reference Group. The working party also developed its recommendations which formed their contribution to the strategic and implementation plan. Six key issues were nominated as relevant.

Diagnosis and Early Intervention key issues identified

Screening

Primary health care

Treatment patterns

Consumer involvement

Quality assurance

Monitoring and surveillance

Screening: Population based programs

Only two cancer sites have been judged to date as suitable for population based screening programs on the basis of their likelihood in reducing cancer mortality. These are breast and cervical cancer.

However for even a small impact on mortality both require substantial increases in the proportion of women being screened. A study of cervical cancer screening undertaken in Australia found while 78% of women had been screened at some time for cervical cancer, only 51% said this had taken place in the past two years as recommended.[86] This meant that only 50% of potential squamous cell carcinomas of the cervix were being prevented compared to the 90% demonstrated by some overseas programs. To improve this situation, the Organised Approach to Preventing Cancer of the Cervix (OAPCC) was established by Commonwealth and State Governments. It has some specific aims which include:

- increasing the participation in regular Pap tests by women in the target population (18–69 years);
- improving the quality and reliability of the cervical screening pathway and management of women with screen detected abnormalities;
- monitoring and evaluating the effectiveness of all elements of the screening pathway.

As a result of the efforts of this program a number of improvements in the practices of health professionals have been effected:

> Cervical cancer campaigns at the state and federal level have led to improved participation rates as measured by Medicare data in the Department of Human Services and Health.

The NHMRC has prepared *Guidelines for the Management of Women with Screen Detected Abnormalities* which was distributed to all gynaecologists and pathologists.

A two year trial of the draft performance standards developed for laboratories is under way.

As well as undertaking publicity campaigns to improve women's understanding of cervical screening, most States and Territories, including the ACT have established cervical cytology registries to enable a recall system to be implemented.

The Program for the Early Detection of Breast Cancer was begun in 1990 by the Commonwealth and State governments as a nation–wide population screening initiative. It seeks to raise the participation rate of women aged between 50 and 69 years in regular two–year screening mammography. The national program has set new standards for quality assurance with the development of detailed protocols for every component of service. The objective of a 70% participation rate is being steadily approached in the ACT with incremental improvements each year.

Screening for tumours at other sites

Population based screening programs for colorectal and prostate cancer have been discussed in both medical circles and the popular press. However to date the evidence does not support such a public health policy [87] The two screening tests available for colorectal cancer – sigmoidoscopy and an occult blood in the faeces test are available for high risk individuals defined clinically as those with a family history of the disease. No screening test of sufficient accuracy for use at a cancer population level is available at this time for prostate cancer, although serum prostatic specific antigen (PSA) is being increasingly used.

The NHMRC Working Party on Preventive Activities in the Health Care System is currently developing recommendations about screening for lung, testicular, ovarian, pancreatic and oral cancers as well as colorectal and prostate.

Are there alternatives to screening by tumour sites?

The Australian Cancer Society has examined the identification of key risk factors as an alternative approach. The strategies include:

- reduction of tobacco consumption
- adoption of a prudent diet
- reduction to sun exposure
- reduced alcohol intake

Primary health care

Role of the GP in cancer prevention and early detection activities

It is believed by most that the GP has the greatest potential for systematic delivery of cancer prevention and early detection services to large populations.[88] [89]However discussion in the literature has acknowledged a number of significant problems in the current role undertaken by GPs. Screening and preventive practices appear to be variable as the aforementioned statistics on cervical and breast screening demonstrate.[90] A US study in 1990 did find that overall GP's had a commitment to regular cancer screening. Ninety per cent reported they routinely ordered or performed almost all the recommended examinations for colon, breast, cervical, prostate and skin cancers for asymptomatic patients fifty years and older.[91] Another U.S. study found that computer generated reminders of screening tests significantly improved GP screening practices.

It must be acknowledged however that there is still no agreement in Australia on the recommended screening examinations for all these main tumour sites. The National Health and Medical Research Council (NHMRC) is slowly building an authoritative voice in regard to this matter with the assistance of the Cancer Network and professional bodies. Information on breast cancer and cervical screening practices has now been disseminated to the medical professional nationwide. It is anticipated that the review of colonic screening (which has been awaiting the results of meta-analysis from world-wide studies) will enable dissemination of guidelines. Prostate screening practices remain an area of controversy which will require practitioners to continue to look to their individual professional bodies for guidance for some time to come. Projects being undertaken with the leadership of the Anti-Cancer Council of Victoria and the Health Enhancement Unit with the Public Health Branch of the Victorian Department of Health and Community Services will also assist in responding to the needs of general practitioners in this country. An integrated cancer risk assessment resource for GP's is being developed which amongst other matters is examining the educational needs of GPs about cancer prevention in general

Concern has been expressed about the extent of physician knowledge in regard to cancer symptoms and diagnosis.[92] [93]A 1991 Australian study[94] found medical graduates were poorly prepared for preventive practice, frequently not understanding the epidemiological concepts necessary to critically appraise the benefits and risks of cancer screening. Surveys in the U.S. have confirmed misunderstandings about cancer screening and risk factors among general practitioners[95].[96] [97]

The Australian study also found a disturbing bias in medical student knowledge. A high number of graduates (44%) estimated (incorrectly) that lung cancer had a 50% five year survival rate and 16.3% would treat metastatic lung cancer with curative intent.[98] Opportunities for obtaining experience in the various areas of cancer management, namely medical, surgical and radiotherapy vary widely from state to state. Two of the authors Professors Tattersall and Langlands stressed the importance of professional education. Undergraduate experience is the major determinant of a life-time approach to cancer. This may not be changed with post graduate training as cancer management and control does not fall squarely on any of the individual postgraduate colleges or educational bodies.

The Evidence Based Medicine Working Group in the United States has begun to identify the new skills physicians now need. There is a need for a paradigm shift away from the "intuitive, unsystematic, clinical experience and pathophysiological rationale " and towards the examination of evidence from clinical research. This requires new ways of thinking and learning including a capacity to undertake efficient literature searches and the application of formal rules of evidence evaluating the clinical literature. Skills of problem defining, searching, evaluating and applying original medical literature need to be taught in medical curriculum.[99]

A report by the House of Representatives on the Management and Treatment of Breast Cancer in discussing ways to improve the current situation made the following recommendation as a result of its concern about the paucity of undergraduate and graduate exposure to cancer in general.

> *3.14 The Committee recommends that greater and urgent attention be given by the Royal Australian College of General Practitioners to address the lack of exposure by general practitioners to training about the management and treatment of cancer, and in particular breast cancer. That training should include: the need to encourage both self-examination of breasts and regular examination by the general practitioners, the need to encourage appropriate patients to undergo mammography screening, the role of multidisciplinary teams in the diagnosis, management and treatment of breast cancer and appropriate referral to such teams, and, aspects on the benefits to the patient and their family of counselling and support groups.*[100]

Treatment patterns

Studies in the US have identified a number of practice barriers which were sometimes patient created, sometimes healthcare obstacles, and other times practitioner generated. Both Kaluzny and Wender[101] [102]in discussing their results asserted that there was a need for a fundamental understanding of the larger organisational context in which the GP is working. The role of the GP is being examined in a number of quarters throughout Australia[103] [104] [105] [106] [107] [108]While rigorous studies have still to be developed to evaluate cancer management and control by GPs, the research themes being explored raise not only their role in secondary prevention but the significance of their role in the primary health care team, for supportive care and most particularly palliative care. In the ACT the opportunity for the Division of GP's to take an active role in this task was acknowledged by the Reference Group and the working parties of the strategic planning process.

Multidisciplinary clinics have been recommended as the most suitable best practice approach (Oxford research team) providing a blueprint for cancer services in general[109] [110] [111] In Australia the National Breast Cancer centre is seeking to develop a template for breast cancer management which some see could be extended to other tumour sites. In Canberra a multidisciplinary framework is established already with a common clinical meeting and consultative tumour clinics meeting for lymphomas and head and neck tumours. Discussions are underway to explore the multidisciplinary management of breast cancer.

The recent House of Representatives Report on the Management and Treatment of Breast Cancer in Australia, discussing the challenges for optimal breast cancer treatment, affirmed this approach, as have both expert committees in the U.S. and U.K. [112] [113] [114]

> *Evidence presented to the Inquiry leads to the conclusion that the determining factor in the best management and treatment of breast cancer today is to have sufficient number of accredited, specialist multidisciplinary teams established around Australia that women in country and urban areas can easily access.*

> *Such team must provide a continuum of treatment which begins with diagnosis, incorporates currently informed treatment decisions, and provides access to counselling services. By providing this broad range of services the teams will take into account, not only the medical and surgical needs of their patients, but their emotional and psycho-social needs as well.*
> *In addition it is considered essential that this continuum of treatment incorporate the active participation of the woman in her management and treatment plan...*
> *It is important to emphasise that this management and treatment model is not seen as operating in isolation, rather as operating within a larger management model which encompasses community based services. Clear lines of communication need to be established between the multidisciplinary team, the patient's general practitioner, and when appropriate, palliative and hospice care service. (pg xviii-xix)*

Consumer involvement - the patient as partner.

The Consumers' Health Forum stresses that asking for consumer view needs to be seen in the context of *how* they are sought, *by whom* and in *what context.* Participation implies not only sharing of information and opinion, but also decision-making power: *"Joint problem-solving, joint decision-making, joint responsibility."*[115]

A report from The National Centre for Epidemiology and Population Health (NCEPH) *Improving Australia's Health* suggested the following standards for consumer involvement and community participation..[116]

> **Standards for consumer involvement and community participation**
>
> **Consumer involvement**
>
> *1) Patients and consumers participate actively in their own health care to a degree with which they are comfortable and are fully supported in doing so.*
>
> *2) There are opportunities and support for consumer and community involvement in the planning, management and evaluation of the health services used by them*
>
> **Community participation**
>
> *Opportunities and support are provided for organisations and consumers in local communities to develop an overview of health planning issues.*
>
> *This should encompass health care needs, health promotion opportunities and health funding pressures as they relate to their communities.*
>
> *They should be able to participate at an area-wide level in determining priorities and strategies*

Canberra people living with cancer are currently well served by the evolving participatory practices being developed with the encouragement and support of the ACT health system.

The culture of consumer involvement in treatment planning is well established within Woden Valley Hospital Cancer Services notwithstanding the acknowledged problems surrounding health literacy challenges. The formation of the Oncology Services Consumer Group in 1994 now provides the added opportunity with appropriate administrative support for planning involvement in service delivery. Significant examples of consumer input include the ward redevelopment, the Oncology Business Plan and this strategic planning project. Twelve consumers participated with representatives from all agencies within ACT who provide supportive care to people with a cancer diagnosis. They have represented a range of views covering the care continuum. The establishment of an expert cancer advisory group as recommended will enshrine the role in ongoing planning, review and resource allocation decisions.

Canberra has a higher than national average education level and a recent ACT study on attitudes, beliefs and knowledge regarding cancer confirms a health literate picture. Further, a palliative care study currently being undertaken will provide a clear picture of information giving to both patients and their carers and assist with a more comprehensive understanding of patient knowledge of diagnosis, prognosis, treatment aims and other areas of health care.

In 1993, the NHMRC released general guidelines for medical practitioners on providing information to patients, confirming changing community expectations in regard to consumers the involvement of their own care. Their recently released Consumer's Guide to Early Breast Cancer (1995) is a model of its kind that can enable women to confidently discuss their treatment choices with their treating doctor. The issue at the regional level will be to develop mechanisms to ensure patients and doctors are both aware of and use such material. A US study found that patient education materials were poorly used by health professionals, particularly by general practitioners.[117]

The need to evaluate public awareness and use of cancer detection tests was seen by the working party as an important regional issue that should be benchmarked as soon as possible. In this way the effectiveness of health promotion activity can be evaluated as an outcome measure.

Members of the Oncology Services Consumer Group confirmed the results of the Canadian study which found that the majority of people with cancer felt that their needs for information and support were greatest at the time of diagnosis and at the time of surgery:

'Cancer patients' needs for information range from medical to practical to emotional. In general, the people surveyed indicated that existing sources of information dealt more fully with their medical questions, and to a lesser degree with their practical needs. The greatest 'unmet' needs for information were in the area of emotional issues.'[118]

Medical information covered: details of the specific cancers, treatment choices and therapeutic options, detailed descriptions of surgical procedures and specific treatment, information about the physical impact and side–

effects of cancer, of surgery and various treatment forms and details about symptoms, and probabilities of recurrence.

Practical information covered: the need to understand the medical system and hospital procedures in particular, information about the Canadian Cancer Society and other agencies who could provide help together with details about daily living issues of nutrition, homecare, transportation, accommodation and financial assistance for out-of-town patients. Information on legal and employment issues and a list of books and publications of interest.

Emotional issues covered: details about possible emotional reactions to cancer and its treatment, information about how other people have learned to accept a diagnosis of cancer and to live with the fear of recurrence; possible impact on personal and social relations; dealing with lifestyle changes and with concerns about changes in body images; availability of support services and mental health counselling for cancer patients and their families; how to deal with the emotional reactions of family members; the emotional impact of a recurrence of cancer; emotional needs of patients and family members dealing with cancer in an advanced stage.

Patient perceptions and patient cancer care

An Australian study[119] examining those illnesses Australians most feared getting found that cancer was by far the most feared illness, with over 60% of first mentions and 80% when first and second mentions were combined. This reflected similar findings in a Canadian study (Mackillop et al). In the period between the two surveys 1986 and 1993 the concern about cancer had increased. Reasons for fearing it included perceptions about it being incurable and of the pain and suffering experienced. Heart disease, mental illness and AIDS were mentioned by 10% of the sample.

However U.S. studies as summarised by J R Seffrin and Wilson [120] indicate that many myths and misperceptions still cling to cancer, that just hearing the word frightens one in two people, and that more than two thirds consider it the most serious of the major diseases threatening not only their quality of life, but life itself. One in three consider a diagnosis of cancer a death sentence and it is frequently considered the cure is worse than the disease and they ignore symptoms are ignored.[121] Despite this, cancer risks from lifestyle choices of smoking, excess drinking, and high-fat low-fibre diet are still not acknowledged by many.

A patient's knowledge and beliefs about cancer can have a significant impact on how he or she copes with the disease. Given found that patients who believe that cancer can be cured and that their actions may make a critical difference are more likely to comply with therapeutic regimens and recommended behaviours.[122]

The emotional responses to a cancer diagnosis can include anger, disbelief, anxiety, hostility, bitterness and self-pity. Many experience sensations of guilt and inadequacy. [123] [124]Emotional responses such as anxiety and worry can impair cognitive functioning and greatly affect the capacity for cancer patients to establish a partnership with their treating doctor. [125]Age response differences have been found to be marked: middle-aged patients usually regard cancer as disruptive. Elderly people are inclined to consider themselves more vulnerable to cancer and see it as an acceleration of the ageing process.[126] [127]

The patient/doctor relationship

While the question of full disclosure of diagnosis to cancer patients has been the subject of international debate for many years, recent studies have provided a range of new insights. The need for breaking bad news in such a way that the doctor maintains appropriate hope and the communication to the patient becomes a matter of sharing goals was highlighted by both Links & Kramer and Kinzel.[128] [129]Discussion in the literature has raised the need for cultural sensitivity and the problem of informed consent.[130] [131] Two European studies in1994 provided striking evidence where in Spain[132] it was found that 68% of patients were unaware of their diagnosis and in Italy [133]a similar picture was portrayed with 62% with advanced cancer unaware of their diagnosis.

A study by Shapiro et al found there were socio-economic status differences in patients desire for and capacity to obtain information in the clinical encounter.[134] Patients can be highly sensitive to medical behaviour and one study found that evidence of coolness, indifference or insensitivity can create dissatisfaction that in turn affects prognosis[135] Seffrin [136]made the observation as well that medical students harbor more negative feelings about cancer patients than about patients in general and while experience increases doctors confidence the aversion has been well documented. This has special implications for GP management of cancer conditions as is being recommended increasingly by health systems.

Quality assurance

In a National Workshop conducted in August 1988 by the American College of Surgeons and the American Cancer Society [137] the keynote address stressed the need for substantive peer review and professional self examination based on quality of care considerations. To do this physicians and surgeons would need to participate in setting clinical standards. This would mean examining their professional culture notwithstanding the acknowledgment that cultural change was not easily achieved impinging as it does upon individual values, attitudes, beliefs and behaviours.

This workshop has continued to provide a beacon for professional standards in all spheres of cancer care from pathology, cytology, mammography, oncologic imaging and endoscopic use in the areas of early detection to the need for multidisciplinary clinics in treatment and the issues of continuity of care , the problems of developing appropriate clinical indicators and guidelines in clinical practice.[138]

Quality assurance is the key to effective cancer management. However it is currently not possible to assure the public that such procedures are in place. Indeed it cannot be answered for cancer management around Australia as the recent House of Representatives Inquiry into the Management and Treatment of Breast Cancer points out.[139]

'While some medical practitioners have stated that Australian women are being provided with the best management and treatment possible for breast cancer, the evidence gathered by this Inquiry would not support such an assertion.'

The Committee in recommending that multidisciplinary teams, including a pathologist, be established as a matter of urgency suggested that the concept of medical care be expanded beyond the narrow concept of treatment to include a patient perspective which they described as cancer management.

'It is essential that the concept of 'best practice management' incorporates both the active participation of the woman in the decision-making process about her treatment, and strong links with general practitioners, counsellors and community based support services.'[140]

Monitoring and surveillance

This issue was explored in more depth by the Treatment working party who examined the challenge of establishing a hospital-based cancer registry as part of the core element of a monitoring and surveillance function in cancer care and control. Nonetheless the diagnosis and early intervention working party recognised that an ongoing expert advisory group with public accountability needed to be established as a matter of some urgency if any of the issues discussed above were to have the requisite leadership to ensure implementation at the regional level.

Diagnosis and early intervention recommendations from working party

Diagnosis and early intervention recommendations from working party

Screening

1. Evaluate current breast and cervix screening programs for effectiveness in reaching target populations and compliance with national guidelines.

2. Expand public education campaigns to educate women in the community about the benefits of screening and target those most at risk e.g. older women, women from Aboriginal and non-English speaking backgrounds.

3. Encourage informed community debate about limitations and benefits of screening for cancer.

Primary health care teams

4.Evaluation of GP cancer screening practices should be undertaken

5.Programs should be initiated to redress the deficiency regarding cancer control and management in undergraduate and postgraduate teaching identified by Australian studies.

6.The Division of GP's be asked to emphasise and facilitate close communication between primary care and specialist cancer services.

Treatment patterns:

7.That the formation of multi-disciplinary clinics be encouraged for the tumour sites of lung, breast cancer, colorectal and gynaecological.

8. Expert groups be established to develop regional practise guide-lines for the appropriate tumour sites.

9 That in developing cancer care in the ACT an integrated comprehensive cancer service should be developed focused on the existing Woden Valley Hospital services with appropriate outreach facilities in the region.

Consumer involvement:

10.That the Cancer Society be encouraged to conduct regular education campaigns to inform the public about early warning symptoms of cancer.

11. That the needs of people living with cancer be examined in a systematic way.

12. The needs of cancer patients for medical, practical and emotional information continue to be addressed.

13. That informed community debate be encouraged around attitudes and beliefs regarding cancer.

14 National guidelines for the diagnosis of impalpable and palpable breast lesions be adhered to in the ACT and region.

15. That the ACT press for the undertaking of the standardisation of clinical information to pathologists.

16. That a hospital-based cancer registry be established to monitor treatment practices and outcomes.

Monitoring and surveillance:

17.A reference committee be established to provide monitoring and surveillance of data for cancer care and control.

Project Discussion

Opinion in expert quarters around the world now acknowledges that curing cancer is still only on the scientific horizon. The challenge therefore is to live well with this limitation. Culturally, this is difficult given the enormous medical successes of the past fifty years. For the medical profession itself, in the rather stratified social organisation of its subculture where the objective of cure is the driving force, the very real problem of perceived "failure" needs to be addressed in both a sociological and a cultural sense. This problem extends of course beyond cancer to such other situations as those admitted to Intensive Care, or undergoing renal dialysis, or diagnosed with a psychiatric condition for whom cure is not possible.

How to acknowledge with and to the medical profession the success of cancer care the thoughtful citizen may ask? What is it in the care of the cancer patient that medicine can perhaps learn about its practice – at the end of the twentieth century in the western world at least. These are questions of philosophy and ethics. They have not actually been addressed directly by this project although there may be scope for some intellectual leadership from the ANU's Centre for Continuing Education in co-sponsoring a forum. Discussing and answering such questions however is part of our civic life and in turns informs our political values and priorities. An ageing population sharpens the moral debate.

How does a patient's experience of his or her diagnosis and early intervention affect treatment choice and possibly manner of dying? What do we consider patient needs to actually be at the time of diagnosis? What is the subtle impact on community perceptions when individuals have been through 'the cancer experience' with a loved one? As increasing numbers of people in the community find that parents, partners, and friends have such an experience what is the public health view that emerges may be another way to present the question.

At the time of diagnosis, provision of professional counselling services available to assist in clarification of the emotional impact and the evaluation of psychological need is haphazard. There is in the literature an abundant description of the particular range of skills required to effectively respond to the psycho-social needs of persons diagnosed with cancer. However, amongst health professionals there is very little discussion as to who best provides this service – a trained volunteer counsellor, a nurse, a psychologist, a social worker, a general practitioner? Certainly it is very clear that no appropriate professional training is available in Australia to the above groups – people learn on the job, generally best by being a member of a multidisciplinary oncology team in a teaching hospital setting. While non government support both here in Australia and the UK has been important in providing patient supportive care it has thereby marginalised both the need for and perceptions of professional role and development. The old 'charity worker' of the nineteenth century lurks in the supportive care presented by these agencies, albeit a 'tissues and cup of tea' variation.

The role of general practice needs clarifying. Clearly the diagnostic pathway is the single most important factor in optimising treatments for various tumours. Which member of the medical team is best suited to determining what tests are undertaken, when, by whom is one area requiring clarification both in terms of patient comfort, and minimising waste of expensive diagnostic procedures. It not infrequently occurs that similar tests are ordered by both general practitioners and medical specialists because treatment goals were vague or unclear. Monitoring and surveillance of patient medical care is another area that needs clarification so that general practitioners mirror specialist practice. While letters are sent to GPs by most specialists, many patients are unaware of the extent of both the practice and information exchanged between the tertiary and primary health care sector. Only a few patients get to read the exchange or keep a medical file themselves. One of our oncology consumers explains she has two GP's –the female one who diagnosed her cancer and the local family GP who practises nearby. She photocopies the specialist letter she obtains from her 'women's ' GP who continues to manage her cancer care and takes a copy to the family GP thereby ensuing a complete record – 'just in case something goes wrong; at the weekends' she says.

Records to the GP can in the end be inches thick. Do they get time to read them with a ten minute appointment schedule? Would a survey of the information exchange practices between the differing layers of medicine help both them, patients, and the health administrators understand the real nature of the GP/specialist relationship. What kind of patient record is needed to best inform all members of the team of the patient in context? What are the privacy aspects of widely circulating records occurs in cancer care when treatment extends over long periods of time.

What is the role of the multidisciplinary team in the medical relationship – both in the tertiary and primary sector. The assertion by general practitioners that they have skills to undertake psychological and social assessments is not born out either by their training in regard to effective counselling nor in their current knowledge and understanding of community resources or interdisciplinary referrals. Again, the short time slot that drives most general practice does not encourage effective family decision making for complex chronic conditions such as cancer management. That these are family matters is born out by the fact that 50% of people diagnosed with cancer die of their condition. It is not a health disease that can be managed by the individual alone. It is therefore from the beginning a family/friends matter if full understanding and knowledge is to be gained by those involved in long–term care.

The community attitudes and beliefs that drive concern about cancer – the fear of pain and suffering – are community health matters that specialists (surgeons and physicians) need to address in partnership with others in the fields of health education to address. Not only is there potential health benefit in greater community understanding, but there is also a potential efficiency in the time spent by the medical profession in the individual case management situation. Prejudice and fear are potent emotions that affect cognitive processes and influence both knowledge retained and capacity to make decisions.

Social workers are attached as members of multidisciplinary teams within Woden Valley Hospital and Calvary Hospital and undertake many of the emotional support functions outlined in the Canadian Cancer Society study as part of their professional role. However, sustained pressures to cut costs have impacted on the culture of service delivery developed over the past decade and this professional group is particularly conscious of the need to undertake a review of service provision to respond to increasing caseloads within a shrinking budget allocation.

Quality assurance needs to be undertaken in a systematic fashion throughout Australia as the parliamentary inquiry has highlighted. The ACT region could participate in the development of such an approach and certainly a formal examination of the issues of quality assurance in cancer care are essential if proposals for developing clinical performance contracts in an Australian setting are to be developed. Indeed providing the kind of focus of the aforementioned US workshop could be a most useful best practice project in the health outcomes initiatives currently being supported by the Commonwealth.

Treatment and Management Working Party

Goal: To develop and oversee the implementation of a plan for cancer data collection system.

Outcome: The treatment working party made the decision to focus on the issue that was central to ensuing quality clinical treatment, namely the establishment of a hospital based cancer registry. Linkage between a hospital–based system and palliative care data was also seen as an important goal. The project officer obtained literature around the topic and drafted a paper for report to the Reference Group outlining the problems inherent in establishing these systems. It is this aspect that forms the early part of the discussion of the literature that follows

However, for the purposes of this paper, contributions from a variety of sources have been included to round out perspectives on cancer treatment and management. Discussion therefore includes the following:

- some of the issues raised by clinical members of the treatment working party when developing their business plan for Oncology Services;
- discussions from the Joint Working Party Consultative Planning Workshop where key treatment issues were addressed by over fifty people engaged in cancer management in the ACT;
- some of the literature covered in the Issues Papers of the Diagnosis and Early Intervention and the Rehabilitation & Extended Care working parties. Because the care continuum is a conceptual artifact that does not fully represent practice, there is overlap and some issues therefore will not be revisited in detail.
- various national discussions including recent Parliamentary Inquiry;
- the Australian Institute for Health & Welfare's specification of data requirements for the National Health Goals and Targets.

Cancer treatment and management key issues identified

Establishing a hospital based cancer registry

Identifying ACT/NSW cancer services

Developing best practice

Assessing treatment outcomes

Acknowledging patients key role in treatment decisions

Developing multidisciplinary care

Community support services

Professional education

Relationship between acute hospital and outpatient medical management

Data systems in cancer treatment facilities: a hospital-based cancer registry.

Background:

Acknowledgment of the need for hospital-based registries has been widespread as the various Inquiries into cancer care in Australia indicate. The recent Senate (1994) Inquiry [141] said clearly

7.63 Evidence to the Committee suggested that hospital-based cancer registries need to be established. The Committee was told that few, if any, hospitals in Australia have cancer registries which contain information on the number and status of patients with cancer treated at the institution. In the absence of hospital-based registries or data on outcomes in clinically relevant groupings from a central registry, a doctor's notes may be the only record of the precise treatment given to a cancer patient. The establishment of these registries is needed so that data relating to treatment outcomes can be assessed so that efficiency of cancer care delivery can be measured.

7.65 The Committee believes that priority should be given to establishing hospital-based cancer registries to work in conjunction with state/territory central cancer registries. These registries should collect information on clinical characteristics, treatment, and outcomes so that a system of monitoring the outcomes of cancer treatment can be established. ...

The House of Representative Report (1995) re-iterated:

'Data collection

3.42 Without proper data collection it is impossible to assess the outcomes of diagnoses, treatment, and management. Cancer registers should be funded in hospitals to gather a body of comparable information which should feed into State/Federal registers.

3.43 It is also necessary for a comprehensive national data base on breast cancer to be immediately established and maintained. This data base should include information gathered from hospital and State/Territory registers and could also include data on prevalence and mammography screening.

It is noted that the national conference on hospital-based cancer registries, organised by the Australian Cancer Society on 1 July 1994, recommended that priority be given to establishing hospital-based cancer registries to work in conjunction with State/Territory central cancer registries. the Committee wholeheartedly supports that recommendations. "[142]

At the Executive level, the National Health Goals and Targets Report endorsed the necessity of hospital-based cancer registries

'Gaps in cancer data collections strategies

Priority should be given to establishing hospital-based registers to work in conjunction with State and Territory central cancer registers. The Commonwealth and States/Territories need to develop a plan for the staged implementation of these registers in major teaching hospitals by the end of 1996 and in private hospitals by

1999. These registers should collect information in clinical characteristics, stage, treatment and outcomes to best monitor the outcomes of cancer treatment.'[143]

At the professional level, both the Australian Cancer Society and the Clinical Oncology Society of Australia have publicly proposed the urgent establishment of such a data system. An Outcomes Report in July 1994 from the National Conference on Hospital Based Cancer Registries heard the Commonwealth's Chief Medical Officer, Dr Tony Adams, acknowledged that there was very little Australian data from which to prepare outcome measures.[144]

> *ACT Health has endorsed these recommendations by currently undertaking the development work for a hospital based cancer registry to commence data collections this year. This ensures the ACT will have amongst the most comprehensive cancer data collection in the country.*
> *In time it will provide the framework for effective planning of services for our rapidly ageing population together with the tools for clinical evaluation of cancer treatment.*

Types of cancer registries

Population Cancer Registries:

A national cancer registry system is now available in Australia with a network of population based cancer registries functioning within all States and Territories. This means it is possible to obtain a comprehensive picture of cancer incidence, mortality and case–fatality data throughout the country; subject of course to sufficient resourcing to maintain data collections and to allow for timely analysis and reportage of cancer statistics. The ACT was the last jurisdiction in Australia to legislate to enable cancer registration and establish a cancer registry. Prior to this ACT cancer registrations were counted with New South Wales.

The effect of delays in reporting cancer statistics are serious and have been clearly described in the report "Better Health Outcomes for Australians" where it was noted that such delays in processing "affect policy development, management of health services, and detection of emerging incidence trends."

Dr Roder, immediate past president of the Australasian Association of Cancer Registries, reporting recently to the Australian Cancer Society noted that data from these collections are already used for the following:

- some planning and evaluation of services
- the investigation of environmental and occupational concerns;
- the assessment of outcomes of specific interventions;
- formal research studies in the fields of cancer aetiology clinical care and environmental health.

He also saw emerging roles developing ; for instance cancer screening can monitor the cancer interval rates and treatment services can be monitored.

Hospital Based Cancer Registries:

The first Australian Conference on Hospital-Based Cancer Registries[145] stressed however that monitoring outcomes of cancer treatment and assessing quality of cancer care was premised on the establishment of hospital-based registries.
It is this registry that enables clinicians to monitor: case survival and more immediate outcomes of care by stage and other prognostic indicators; and patterns of care by stage and related prognostic indicators.

This forms the basis of ongoing quality appraisal. From this information clinicians can assess whether survival rates and other outcomes meet the expectations they have, based on the scientific literature and other information sources. Equally importantly, it enables them to assess the extent to which treatment policies and guidelines are being followed in their hospitals.

The relationship of hospital based and population based cancer registries.

Hospital and population based cancer registries perform complementary roles. Dr Roder at the Cancer Outomes Symposium in May 1994 described the relationship as follows:
Population based registries have the purpose of quantifying community cancer burden; quantifying high risk groups; showing population trends in incidence and mortality survival; and providing data supports for service planning, service evaluation, formal research and reports to environment/occupational health concerns. Data sources and outputs include hospitals, pathology labs, death records, the national death index, and electoral rolls; providing incidence, mortality and case survival.

"Population based registries are important as public health information systems."

Hospital based cancer registries have the purpose of quantifying the hospital cancer burden by tumour site; obtaining case outcomes by stage, treatment patterns by stage; providing a list of unit record number of cases; providing sampling frames in regard to quality of life and other research outcomes; and providing a source of core data for supplementation. Data sources and outputs include population based registries, medical records, and clinicians providing prognostic indicators, case survival and treatment patterns.

"Hospital-based registries are information systems for clinicians to use for monitoring their services and service outcomes. Hospital-based registries indicate the extent to which actual practice concurs with clinical guidelines."[146]

Dr Roder stressed that linkage between the population registry and the hospital registry is critical to check that case ascertainment is complete and to obtain time of death information. Data analysis in South Australia is a shared task with the population-based registry undertaking the more complex procedures. Reporting results however remains within the province of the relevant clinical units and each registry's professional management committee.

Clinical research: Clinical trials.

The national conference on hospital based cancer registries also explored the third tier of a comprehensive data system, namely clinical trials. Discussing the role of clinical research in the new National Health Service in the U.K, Smythe, et al[147] said it is now widely that the most accurate and effective way of evaluating medical treatments is a randomised controlled trial;

'Randomisation avoids bias in the selection of patients, and results on an intention to treat basis ensures that treatment are tested in a way that reflects the realities of clinical practice. Also, effective assessment of new therapeutic strategies is essential to avoid the inappropriate use of scarce resources..'

It is the clinical trial that provides the research basis for evaluating new treatments properly before they are introduced on a wider scale into routine practice. The increasing sponsorship of trials by the pharmaceutical industry however creates particular problems because: they *"are designed to gain a product licence or to show that a new compound has some effect on tumours; they are performed to benefit the company rather than to compare two treatments with the sole intention of improving the provision of health care."*[148]

Clinical trials impact directly on a patient's survival, and ultimately on disease mortality. Moving beyond the debate of the success of new therapies demonstrated in carefully performed trials, Feuer *et al* [149]assert that the ultimate goal of clinical cancer trials is *"an improved survival (and lower mortality) experience for the patient population at large"* and towards that end they have explored statistical models to assess the impact of clinical trials on the survival of the general patient population. The model allowed the research team to determine approximately when survival first began to improve dramatically indicating that improved treatments had become available, and how long it took for survival to level off again indicating that the full population survival impact had been realised.

Barriers to establishing hospital based cancer registries in Australia

Hospital cancer registration is performed widely within the United States in cancer treatment centres.
A number of difficulties have been cited in regard to the establishment of hospital based registries in Australia. Only South Australia has a comprehensive cancer registry system although as noted above the ACT now joins them as the second state/territory with such facilities. Dr Roder, immediate past President of the Australasian Association of Cancer Registries, in a letter to the Commonwealth Department of Health made the following pertinent remarks:

'We live in a culture of cost-cutting. Hospital administrators are pre-occupied with questions of how to cope with cuts. The development of hospital registries is out of step with their creed. Added to this is the problem of who should pay. Is it the hospital, the state health authority, or the Commonwealth? Should the money come from the research allocation, the health-service allocation, or what? Should it be shared in some way, and if so, how? Momentum cannot be gained for the introduction of these registries when there is such confusion.

A further problem is the knee-jerk concern among clinicians that these registries may reduce their professional independence and tie them down to form filling.... Another problem is a lack of knowledge on how to put these registry systems together...' few people in Australia have had much experience in this field. The process is very different from that applying to state registries....
At the level of our health bureaucracies, there is state support for quality appraisal and even hospital-based cancer registries. But there would be limited understanding of the nature of these registries, how they work, and what realistically then can be expected to do. This appears to create major difficulties moving beyond the generalities to the specifics.'

At the moment, we have stated support for hospital registries from the Australian Cancer Society, the Clinical Oncology Society of Australia, and Senate and House of Representatives reports on breast cancer management, and in the National Health Goals and Targets. There are precedents from their successful operation in the United States and South Australia. Few would disagree with them in principle. But unless there is an energy focus at the national level for their development, some sort of resource inducement, and a sharing of the practical experience gained in this country and overseas in making them work, then I believe little or no progress will be made."

Other data collections:

Currently the ACT collects information from the Diagnostic Related Groups (DRG's) of hospital impatient records; the cytology register as well as some mammographic details although this is only a partial collection. The Home Based Palliative Care Program also records its activity data but this has not yet been dovetailed into other systems to provide efficient data evaluation. The Hospice has received funding this year to develop its own data collection.

Cancer data currently available in the A.C.T.

The ACT established its own population based cancer registry in July 1994. Prior to that it relied on the NSW Cancer registry to collect details for the ACT which however was not a comprehensive system as notification was not compulsory. We are therefore now able to begin comprehensive collection of details on incidence, mortality and case survival.

However we are still unable to determine yet with any accuracy of those diagnosed with cancer in the ACT how many received their treatment in the Territory and how many went interstate. The hospital-based registry, located ideally across all three hospital sites within the territory will be able to provide this detail. Cancer prevalence, those living with cancer, could be built into the data picture as data accumulates.

Again however, we are unable to answer the basic questions for service planning: of the 300 persons who died of cancer last year in the ACT how many obtained a palliative care service? What were the treatment modalities undertaken for those persons diagnosed with cervical cancer? Did they receive all or part of their treatment here in Canberra, or did they go elsewhere? What treatment modalities did those diagnosed with colorectal cancer receive?

The current hospital data systems do not provide such detailed information at the impatient level and do not fully collect outpatient clinical details.

The following issues were developed after the working party had reported back to the Reference Committee and the support of the Minister for the establishment of a hospital based cancer registry had been obtained. Much of this needs material was obtained or reflects discussion undertaken at the Joint Working Party Planning Session which is recorded in a later section of the paper.

Developing best practice

Best practice in the discussion at the Joint Working Party Planning workshop embraced a number of elements: ensuring comprehensive agreed treatment protocols were established; that clinical practice became increasingly based on evidence from research; that an ongoing climate of peer evaluation of clinical practice was created ; that quality of life measures became incorporated as routine practice; and that evaluation of service coordination ensured maximum health benefits to both individuals and populations (a further discussion follows in the planning section).

The NHMRC has been providing national leadership in the development and implementation of clinical practice guidelines, which they describe as 'systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances.' The purpose of guidelines is to achieve better health outcomes by improving and reducing variability in the practice of health professionals and by better informing consumers about treatment options. They can also be used in the broader education of practitioners and the community and can contribute to quality assurance processes ; as well as assisting in legal and ethical disputes.[150]

In 1991 the Australian Health Ministers Advisory Council (AHMAC) asked the NHMRC to develop processes for promoting best practice linked to outcomes and effective cost management. The NHMRC subsequently established a Standing Committee of the National Health Advisory Committee (formerly Health Care Committee) named now the Quality of Care and Health Outcomes Committee (QCHOC).

This committee has examined overseas development in clinical practice guidelines and outcomes activities with the aim of adapting these approaches to the Australian setting. In October 1995 they published both the Guidelines for the Development and Implementation of Clinical Practice Guidelines together with the first of the cancer clinical practice and consumer guidelines in the management of early breast cancer .[151] [152]These three documents provide a model of best practice for developing guidelines for a range of conditions and procedures. The term 'clinical' is '*intended to be inclusive of health care providers, not just medical practitioners.*'[153]

A good deal of research has been undertaken regarding quality of life assessment in cancer treatment protocols. Accurate quality of life information could, it has been suggested, make a major contribution to improving the management of cancer patients.[154] A Swedish study made the point however that the psychosocial research on cancer patients that has been undertaken has in the main focussed on short–term reactions to diagnosis and treatment in impatient hospital settings.[155]

Assessing treatment outcomes

With the establishment of agreed best practice protocols and the hospital based cancer registry ongoing quality appraisal is possible. The information obtained by the registry can enable clinicians to assess whether survival rates and other outcomes meet expectations, based on the scientific literature and information sources as the NHMRC Guidelines. This of course assumes that treatment policies and guidelines have been formalised within the clinical setting.

A study by Hand *et al.* (1991)[156] illustrates the effectiveness of hospital registries in determining variables associated with the quality of care for breast cancer patients. Specific guidelines of care have been promulgated in the US for breast cancer:

- diagnosis is made at an early stage,
- hormone receptor levels in tumour tissue are determined,
- adjuvant therapy is given to patients with stage II (node positive) neoplasms,
- radiation therapy is given to patients with stage I & II neoplasms treated with partial mastectomy,
- axillary lymph node dissection is done as part of the surgical treatment of patients with stage I & II neoplasms.

This prospective study examined the pattern of care in 99 Illinois hospitals and enabled a detailed examination of their adherence to the above guidelines. Compliance with the first three guidelines was good but compliance was low for the last two standards.

A retrospective study by Hand *et al.* (1993)[157] of cancer registry data collected from patients with ovarian carcinoma diagnosed at Illinois hospitals over 5 years in the 1980s described the statewide patterns of staging procedures, clinical management and survival outcome. It gave an insight into the present–day management of patients with ovarian carcinoma, for instance published recommendations for extensive surgery for pathological staging were not usually followed although recommendations for combination chemotherapy were usually followed.

These two studies illustrate the use of cancer registries for large patterns of care research. The hospital registry is used intra murally by an institution to examine its own performance in terms of external standard guidelines and also to identify cases with unexpectedly poor outcomes, or bizarre treatment profiles for targeting in case-note audits.

The role of the patient in decision-making

The Oncology Services Business Plan nominated one of its key objectives as the need to recognise the key role of the patient in treatment decisions.

The NHMRC in developing the consumer guide for early breast cancer established a Womens Subgroup as an expert group to assist in the development of its guidelines. The Committee began by commissioning a review of all available consumer literature regarding women's experiences with breast cancer. This led to the identification of 400 publications in the fields of medicine, nursing, social work, psychology, social policy, psychiatry and health economics. A focus on the consumer experience as detailed in the literature was then obtained – interestingly this was forty six studies of which only four were Australian. *No studies were located that were initiated or conducted by women themselves.*

The issues identified by the working party from the literature covered the following topics:

- information
- communication between women and clinicians
- choice and autonomy
- support
- outcomes
- treatment process
- access issues
- women with recurrent metastatic disease.

The subgroup, asking whether women and health professionals have a shared understanding of the psycho-social issues, made the following point:

"The studies located in this search indicated that the major issues of concern to women were survival, fear of recurrence, treatment issues, changes in life contact and acceptance of illness (Northouse et al, Lovey and Klaich.) These themes also emerge from the personal accounts. Northouse, however argues that the predominant concerns of the professional literature have been self esteem, body image and sexuality. Pursuing a similar theme, Alderson et al suggest that the professional literature has been overly concerned with conceptualising the psychosocial issues facing women with breast cancer in clinical terms, for example, as anxiety and stress. The ways in which we conceptualise the psycho-social concerns of women with breast cancer are important since they influence how and by whom we believe professional support should be provided. If women's primary concerns are thought to be associated with self esteem, anxiety, body image and sexuality, an emphasis on personal counselling and specialist psychiatric care would be appropriate. In contrast, if women's concerns are believed to be primarily related to treatment issues, changes in life context and so on, emphasis would be more appropriately placed upon short-term crisis counselling, information provision, advocacy and practical support."

Developing multidisciplinary care

The parliamentary report on the Management and Treatment of Breast Cancer stressed the need for greater multidisciplinary care in cancer management.
The Government Response[158] to this report gave the matter its first priority and committed itself to the following:

The Government, in association with the States and Territories and relevant professional bodies will develop a proposal to demonstrate the effectiveness of multidisciplinary teams in relation to problems raised in the Report.
An assessment of the effectiveness of multi–disciplinary teams to address the issues raised would need to encompass:

- documentation of current multi–disciplinary practice, especially with respect to management of composition of teams; supportive and non–supportive environmental factors; links with other sectors; operation in a number of settings; and evidence for better outcomes.
- an assessment of the potential of the multi–disciplinary team to address some of the structural and funding problems in the current system, including to facilitate the co–ordination of care between and within sectors; to impact on the uptake of best practice guidelines; to support and benefit from outcome oriented hospital–based registries; to operate within current/future hospital and health funding arrangements, especially casemix arrangements.
- the development of options or models, with related guidelines, for the composition and operation of multi–disciplinary teams, with appropriate attention to funding and structural incentives (including accreditation) and links with health and community services.

The Department of Human Services & Health has subsequently commissioned a consultancy to examine multidisciplinary teams in breast cancer management and a report should be available this year.

The professional values of nursing place high priority on the relief of suffering in all its manifestations. The differences in professional culture are nowhere so starkly illustrated as in this matter. Eric Cassel, a physician writing in The New England Journal of Medicine, discussed the nature of suffering and the goals of medicine, remarking that

'The obligation of physicians to relieve human suffering stretches back into antiquity. Despite this fact, little attention is explicitly given to the problem of suffering in medical education, research, or practice...
In discussing the matter of suffering with lay persons, I learned that they were shocked to discover that the problem of suffering was not directly addressed in medical education. My colleagues of a contemplative nature were surprised at how little they knew of the problem and how little thought they had given it, whereas medical students tended to be unsure of the relevance of the issue to their work.
The relief of suffering, it would appear, is considered one of the primary ends of medicine by patients and lay persons, but not by the medical profession. As in the care of the dying, patients and their friends and families do not make a distinction between physical and nonphysical sources of suffering in the same way that doctors do.'[159]

The intellectual concept, that suffering is experienced by the person, not merely by their body relates the psychological to the physical. The psychological and emotional sources of suffering lie in the challenges that *'threaten the intactness of the person as a complex social and psychological entity.'* [160]

This same theme was more graphically put by an Australian patient when she remarked that *'When you come to hospital, everything that has defined your life, everything that sustains you, gives your life value and meaning has to be dumped outside the front door.'*[161]

While tumour control of course is the first priority in cancer care, it is increasingly being recognised in the literature that effective management of the patient should include techniques to maximise the patient's sense of well-being or quality of life. *'In cancer, perhaps more than in any other medical condition, the disease and its treatment become major determinants of the quality of life. It has been suggested that the emotional repercussions far exceed that of any other disease, and that the emotional suffering cancer generates may actually exceed the physical suffering it causes (3) (4).'*[162]

Redd[163] provides a review of the current status of behavioural intervention with adult and pediatric cancer patients. Describing behavioural intervention in cancer therapy, he notes:

> *'Its groundwork is the study of human learning and the clinical application of behaviour theory to psychological disorders and education. Behavioural intervention in oncology has a relatively short history (since the early 1980's) as compared to that in other disorders such as heart disease, gastrointestinal disorders, and diabetes. The main way in which behavioural approaches to intervention differ from more traditional psychotherapeutic methods is their focus on change through the acquisition (i.e. learning) of skills and ways of behaving that are more adaptive than the individual's prior mode of behaviour. The goal is not to uncover and/or resolve deep conflicts in the psyche but rather to teach the individual more effective ways of coping. In a sense the therapist is a teacher or coach, providing the patient with specific skills. Although psychologists have been the primary champions of behavioural intervention in oncology, the techniques have been effectively used by nurses, physicians, social workers and other health-care professionals. ...behavioural intervention has been used to treat a variety of problems including pain, anxiety, insomnia and treatment non compliance, to name but three. But by far the best known application of behavioural medicine in oncology has been in the control of nausea and vomiting associated with chemotherapy.'* (p 111-112)

The focus on rehabilitation in cancer care up to and including those with a palliative prognosis requires assessment of need within the context of an individual's familial and societal roles. At the same time cancer treatment of its nature frequently requires many changes in care teams as people move between different treatment modalities. Providing psychosocial assessment and care, assisting in ensuring continuity of care between teams and between health tiers and assisting individuals and their key family and friendship supports to comprehend the treatment process is one of the roles and function of the social work team member. The other is to provide the health care team with an understanding of the psychosocial implications for some patients and their families.

> *'Rehabilitation and continuing care must be equally important partners with prevention, detection, diagnosis and treatment. People fear cancer not only for the treatments used against it, but because of its physical, psychological, social and economic sequelae. To manage these effects, they must be anticipated, planned for, and monitored as a standard component of overall disease management.'*[164]

The role of support groups in cancer care is now well established and a recent article summarising the discussion examining the concepts and types of support groups stressed that facilitators leading such groups need particular qualities and knowledge including of course a knowledge base in all aspects of cancer care. Such work is beginning to describe the facilitator of cancer-related groups as "oncotherapist" and either nursing or social work are recognised as suitable professional bases for developing these support needs.[165]

The Joint Planning Consultative workshop acknowledged that effective patient care needed to consider more than individual medical treatment and a further discussion is available in the planning section.

Community support services

Practical information

Canberra has some well established support services for cancer patients undergoing treatment for example, the regional community service organisations provide an effective network of voluntary transport for patients receiving chemotherapy or radiotherapy who may not be well enough to drive themselves home. However, consumer representatives urged a brochure be developed that consolidated community service information for cancer patients for inclusion in the Patient Information Kit. The Oncology Services Network directory was considered an appropriate basis for a companion patient document for distribution to cancer patients.

The Canadian Cancer Society study identified the following information needs:

- information about 'daily living' issues including nutrition, homecare, transportation and so on
- specific information about transportation, accommodation, and financial assistance for out-of-town patients
- information on legal and employment issues pertaining to cancer patients
- lists of books and publications of interest to cancer patients and their families.

Oncology social workers in the ACT do provide information on the above matters. However the practice of contacting all new patients to Oncology Services has ceased due to the increase in numbers without any commensurate increasing in service provision time. They also provide a reading list and have a reference and browsing cabinet of current popular books on living with cancer. Referral to the ACT Cancer Society is frequently made for information needs as it has an excellent library which includes audio-visual material for both families and children.

Employment and financial issues

No survey has been published in Australia that provides an assessment of the impact of employment and financial issues on the quality of life of those living with cancer. The issues are covered more fully in the next section.

Professional education

The draft specification of data requirements for assessing progress towards national health goals and targets identifies education and training for health professionals as one of the nominated goals. ACT consumer representatives have expressed concern that while the salaried oncology specialists have the benefit of being able to access the Private Practice Medical Trust Fund, the nursing team sells chocolates and runs a monthly stall to raise funds for the continuing education of oncology nurse specialists which has to be undertaken in Sydney in a live–in residential course.

Oncology social workers and other allied health practitioners in the ACT have minimal access to professional training and most practitioners have to pay for their own education including attendance at conferences and workshops which in the main needs to be undertaken interstate. ACT Health and Community Care allocates a global training budget for professional health needs which to date has rarely provided those engaged in actual service provision in Oncology with the support for continuing professional education. Furthermore, those on short–term contracts (increasing numbers in the past few years) have been considered ineligible for such entitlements.

Relationship between acute hospital and outpatient medical management

Acute hospital admissions:

The issue of prompt medical attention at the time of diagnosis was not considered a problem in the ACT although a well designed Australian study to review referral patterns on a comparative regional basis may provide insights as the recent study of breast cancer management in southwest England has done[166]
However, representatives from the Oncology Services Consumer Group (OSCG) raised the issue of the ongoing problem of admission to the acute care hospital when patients have clinical symptoms clearly indicated by either their metastatic disease status or their reaction to treatment protocols or vulnerability to infection as a consequence of treatment (that is when they are immuno–suppressed.)

The following description by consumers is of an anecdotal kind

> *'For patients in sometimes critical conditions to 'wait in Cas' for a bed – sometimes for up to 12 hours and suffer the tedium of an inexperienced resident 'working them up' for admission can be a frustrating experience. Patients in particular have noticed the quality of care at this point in their illness is highly variable depending on whether WVH Cancer Services has a senior Registrar in the unit who can provide a consultancy to Casualty.*

> *The issue is similar for those moving towards a palliative condition as Canberra still does not have the services of a Medical Director nor an experienced registrar to provide a similar consultancy at Casualty.*
>
> *What still frequently occurs for cancer patients in this limbo land is they refer to their GP who may or may not have an adequate medical grasp of their symptoms and rely on their own previous personal experience to case manage themselves through the system.*
>
> *Hospital admission with a fast-track through casualty for patients receiving second or third line oncology treatment is considered by the Oncology Services Consumer Group to be one of the entitlements to quality treatment. The stratagem of using a bottleneck through Casualty as a method for restricting bed numbers is considered unacceptable and at times medically dangerous.'*

Availability of hospital beds/oncology nurse training

Service planning at the regional level relating the epidemiological profile to the numbers of cancer patients receiving outpatient treatment and the predicted bed numbers for in patient treatment was an issue raised by consumer representatives. Consumers were aware of patient experiences not only waiting for hospital admission but being admitted to a non-oncology area that can create substantial individual anxiety. The nursing skills required for seriously ill cancer patients is not always available on other wards –`indeed some members of the working party describe the skills as being at an unacceptable level – and the endless overflow which has seen up to 20–25 % of cancer patients 'queuing' in other wards they considered logically implies a reduction in quality of service and the possibility of compromised care.

Goals and targets

Current goals are focussing on providing national data survival rates in specific tumour sites, namely, breast cancer, cancer of the cervix, colorectal cancer, cancer of the trachea, bronchus and lung, melanoma of the skin and prostate cancer.

It is anticipated that in those places with hospital-based cancer registries, stage-adjusted survival rates for each of the above cancers will soon be developed. To date this is SA and shortly the ACT. Some parts of NSW may also be able to contribute data.

Indicators requiring future research have been nominated as patient satisfaction with treatment of their cancer and possibly reports by women of participation in decision making about, and satisfaction with, and management of their breast cancer. It is noted that the latter will take time to develop.

Indicators in the area of support (as opposed to Prevention and Treatment) that will also require further research are:

- Maintain the quality of life of patients, their carers and families;
- Improve the quality of life and dignity of death, of people with incurable cancer.

Further details are provided in the Information and Data Section of this report.

Project Discussion

The *patient's key role* in treatment decision making has been acknowledged throughout this project and is established practice in ACT Oncology Services. Canberra research being undertaken at present examining information giving practices should give us a detailed picture of this area of cancer care and enable us to evaluate our effectiveness. Furthermore, the activities and performance indicators in the Oncology Services Business Plan may now be better informed by the work of the Women's Perspective Sub–group – that provided consumer to the development of the NHMRC breast cancer guidelines.[167]

Research into the *psychosocial adaptation* to chronic disease has highlighted coping as a critical factor in the mediation of effects of stressful life events. Coping is seen to have three main functions, namely problem, appraisal and emotion focused. Two contrasting conceptual approaches in the literature have been explored, mainly due to the interest of different disciplines:

- The trait approach which conceptualise coping as a stable individual disposition to react in particular ways to certain kinds of situations .
- The process approach which views coping as multidimensional and highlights individual differences depending on the situational aspects, and their appraisal.

One of the key psychological functions of social work support within the oncology team is to provide assistance to individuals to enable them to optimise their coping capacity and strategies by placing their experience within context, examining coping skills already learned, providing critical information as defined by patient need and assisting with emotional responses to optimise appraisal capacity.

Four key issues are interrelated in their need for action in the ACT, namely, developing best practice, assessing treatment outcomes, multidisciplinary care and professional education:

- Best practice protocols will need to take into account the psycho–social treatment elements albeit with the current restraints of still limited research.
- Apart from the quantitative measures of overall and disease free survival times measuring quality of life is considered to be integral to effectively assessing treatment outcomes. The development in 1996 of a hospital–based cancer registry provides the ACT with the opportunity to be at the cutting edge by ensuring that outcomes in this region actually do include the psychosocial dimensions of cancer management nominated as a priority by patients themselves.
- The treatment working party was not able at that point in time to take up the issue of how cancer management (as distinct from simply the provision of medical treatment) is to be evaluated in an outcomes framework. The challenge therefore remains to ensure all the evolving data and information systems together provide a profile of consistent and timely details of *multidisciplinary cancer care across the care continuum.*

- Multidisciplinary care discussed both in the NHMRC working group and the parliamentary inquiries has hopefully sharpened the focus for further professional discussion with health teams in the ACT. The challenge still remains to design services that respond to people's psychological, emotional and social needs and guarantee quality of life to complement in many cases extremely expensive medical treatment regimes.
- That medical care is still of overriding priority here in the ACT is clearly seen in the funding balance; for example, the recently established Bone Marrow Unit, despite its special resource allocation, didnot to ensure funds were available for a social worker in its service allocation, although all other such units around the country have made such provision.

The Oncology Services Business Plan was developed by a multi–disciplinary team comprising staff specialists, nurses, and social workers. The final draft however reflected a most traditional viewpoint of medical treatment in multidisciplinary care as the activities and performance indicators demonstrated. It would appear that medical practitioners are continuing to ignore the debate both in their own literature, elsewhere and in public forums concerning their treatment referral patterns and attitudes to paramedical colleagues.

Oncology Services Business Plan

• **Objective**	• **Strategies**	• **Performance indicators**
• 7.Further develop multi disciplinary care	• a) Establish and support multidisciplinary consultative clinics for target malignancies, e.g. lymphoma, BMT, lung, breast.	• Achievement of target proportion of new case seen within multidisciplinary clinics
	• b) Develop programs for enhancing GP participation in cancer care	• Obtain funding and initiate program within twelve months

- While there is international and national encouragement it will clearly require an assertive professional stance on the part of the mostly female nursing and social work professions if best practice protocols are indeed to incorporate the 'best practice management' that the medical profession is being urged to embrace.[168]
- The opportunities for professional education to examine cancer care across the care continuum and in a multidisciplinary holistic health framework does not yet exist in the ACT. Even in the field of palliative care, where these approaches are best evolved, no leadership has yet emerged to provide such an education forum.
  The other critical dimension of professional education lies in the quality of nursing care provided. A stable, professional structure is imperative to its ongoing development. Short–term agency nursing contracts, as have begun to emerge in some other states, will seriously erode the culture of expertise and care that enables

the subtle and mature experience of providing both the technical nursing skills and responding to people's suffering to continue to be modelled. Professor Beverly Raphael has written at some length about this matter urging administrators to take account in their workforce planning of the special demands on health teams in intensive/palliative care settings and the need for appropriate induction for all staff.

- Social workers in Woden Valley Hospital provide both outpatient and impatient services to patients receiving chemotherapy and radiotherapy as well as the initial post–operative contact. Referral patterns between service areas reflect the medical model however and a patient may have contact with two or three or even more social workers over time. This project has indicated that this approach may not provide optimal psycho–social care and indeed may have contributed to the continuing dominance of the medical model and its treatment emphasis. The review of practice needs to include not only the patterns of referral and the individual case support but a wholesale re–examination of service patterns and practice to better respond to those needs identified in this project.

Monitoring and surveillance of cancer care and control and who provides the leadership is an ongoing issue. Will there be a public reporting function for the hospital–based cancer registry as in the US situation? Population based registries have had a limited role in informing public opinion and debate because they are not interlocked into hospital–based data systems for the purpose of analysis. What relationship will be developed between the recommended Cancer Expert Advisory Group and other suggestions like an Outcomes Council? That a regular, public reporting function be developed is a matter on which there was widespread agreement.

Rehabilitation and Extended Care Working Party

Goal: To develop an Issues Paper on the needs of post cancer treatment patients.

Outcome: The group met seven times from the beginning of March until the end of June 1995. Members of the team brainstormed the issues to begin with, read the Canadian Cancer Society report on Living with Cancer, together with some literature provided by the project officer and with the circulation of the draft paper contributed their comments. Consumer representatives and community support agencies were a strong voice in this group contributing a consumer perspective to the issues raised. The working party when faced with the wide ranging nature of the task and the lack of any rehabilitation model nor any policy or research infrastructure support other than that provided by the project officer, began by following the outline of a Canadian study examining the needs of people living with cancer. The resulting issues paper and further discussion provided the basis of the recommendations made by the working party to the Reference Group which was its contribution to the framework of the strategic and implementation plan. This section reflects the original structure of the issues paper but has been rewritten to include a good deal of extra material from the literature.

A holistic picture of the major rehabilitation needs of people diagnosed with cancer is part of the research program the working party considered necessary to be developed in this area.

The project has dealt in only a peripheral way with the needs of children with cancer; in part because paediatric oncology is not a sub-speciality in Canberra and children who receive treatment here are under the care of oncology physicians in Sydney. Meadows & Hobbie[169] explored the medical consequences of cure and Lansky et al[170] explored the psychosocial consequences in 1985 emphasising then the implications of the medical successes of cancer treatment.

Hollen & Hobbie in a review article in 1995 made the following points about the needs of children:

> *'As survival rates have increased, many late effects have now been documented for survivors of childhood cancer. Late effects from chemotherapy and irradiation following prophlactic central nervous system therapy for lymphoblastic leukemia in children were first suspected in the early 1970's. Late effects fof multi-modality treatments for this growing population of survivors may result in organ compromise or new primary cancers. Possible late effects of chemotherapy and irradiation for children include fibrotic lung damage, myocardial dysfunction, liver damage, cognitive impairment, sterility, cosmetic changes, and second malignancies. these late effects have been reviewed extensively in the past.*
>
> *Most follow-up care in children is complicated by multiple factors, including potential synergistic effects of treatment. For example, four factors associated with the combined treatments of irradiation and the chemotherapeutic drug methotrexate have been documented. These factors are: a) the number of treatment modalities used, b) the combination of treatment modalities utilised (those ptotocols including CNS irradiation appear to the most neurotoxic), c)the total radiation dose (irradiation of 2400 cGy or more caused late effects, so that protocols were changed to 1800 cGy) and d) the sequence of administration (methotrexate during or after CNS irradiation is more neurotoxic than irradiation after methotrexate). This body of knowledge related to potential and existing late effects in children continues to grow.'*[171]

The growing needs of this group have been recognised as a matter requiring attention and the Strategic Plan explicitly makes a commitment to formally examine the matter.

The approaches to the rehabilitation of the cancer patient is an aspect of cancer management for adults that has received very little research and analysis in either the Australian medical or the social sciences literature although quite a deal of attention has begun to be paid to concept of the cancer survivor in the U.S.[172] A review of the literature by Kurtzman in 1988 provided a comprehensive overview of the rehabilitation needs of cancer patients after treatment.

The goals of cancer rehabilitation are

> *'to help the patient to develop to his or her fullest physical, psychological, social, vocational, vocational and educational potential within the limits imposed by the disease and consistent with the treatment plan.'*[173]

The rehabilitation process it is considered should begin at the time of diagnosis and continue through all phases of treatment, including both the patient as a whole and the family unit. The rehabilitation team requires a multidisciplinary approach with an early screening by a rehabilitation coordinator using ideally some such instrument as the Cancer Inventory of Problem Situations.

Rehabilitation and Extended Care key issues identified

Medical management

Psycho–social management

Bereavement services: loss and change

Employment and financial concerns

Community participation

Support of a research program for cancer survivors

Medical management

Working party members living with cancer reported on the problem of non–acute medical needs and the necessary medical care required if an optimum quality of life is to be assured. These include the greater exposure to common infectious diseases during Canberra winters, which can present life threatening problems to the immune suppressed, and the predictable post treatment experiences of

- hair loss and regeneration
- skin /nail infections (fungal)
- muscle deterioration requiring physiotherapy,
- oral health problems
- urological problems due to medication
- visual disturbances caused by infection or drugs
- sexual dysfunction
- hormonal changes
- sterility
- depression, anxiety, panic attacks

Loehrer et al [174]describing the physiologic effects of what in a literature review in 1989 confirmed this picture. There is a decrease in general functioning, decreased energy level, and sometimes second malignancies. Late fractures, aseptic osteonecrosis, stiffness, weakness, decreased mobility, lymphoedema, frozen shoulder, cataracts and irreversible tear–duct fibrosis. Immunologically there is a decreased reactivity to delayed–type hypersensitivity, and depressed lymphocyte response.

The dermatological picture painted by our consumers was representative of the medical portrait of persistent discomfort, induration, pigmented excoriation, digital cutaneous ulcerations, dryness, lesions and plaques, abnormal pigmentation (hair, nails, mucous membranes) monilial infection, dermatitis.

There can be a number of sexual or reproductive implications from infertility to erectile dysfunction, ejaculatory difficulties, vaginal shortening, ovarian fibrosis and testicular atrophy.
Urological problems can include cystitis and nephritis, while endocrine changes, cardiac, pulmonary, vascular and neurological damage can range from the mild to the severe.

Medical information

People living with cancer find there is an ongoing need for medical information about their cancer post treatment.
Questions the working party felt still need to be answered are:

- Do patients consider they received adequate and appropriate information about their cancer at the time of diagnosis – which is identified as the critical time of need?
- What effect has this had for people who felt they have not been adequately informed?
- Do they obtain appropriate information about the physical impact and side–effects of cancer, of surgery and of various treatment forms?
- Do all patients in Canberra receive sufficient information about their symptoms and the probabilities of recurrence in relation to their cancer?

If, as identified in the Canadian study, and other studies, this is a variable matter, what are the consequences for those people and their families living with cancer who have not obtained sufficient information about ongoing second and third line treatment options or their quality of life?

Medical education

Tattersall & Langlands writing in the Medical Journal of Australia in 1993 reiterated the concern that has been expressed for some years about the inadequacy of cancer education for undergraduates in Australia, Europe and North America. They referred to the Edinburgh Declaration of 1988 (at the World Conference on Medical Education) which aimed to change the character of medical education so that "it truly reflects the define needs of the society in which it is situated." Both authors were concerned that the continued orientation of most curricula was around traditional 'departmental–discipline turf rather than community or patient needs' thereby inhibiting the development of clinical service–based integrated teaching and allowing instead conflicting information to be presented without opportunity for resolution.[175]

Pain management

No survey has yet been undertaken here in Canberra of pain management. A palliative care research project about to commence will provide detailed documentation using the Edmonton Symptom Assessment System (ESAS) on a group of patients living with a poor prognosis and The ACT Care Continuum & Health Outcomes Project (Shadbolt B:1995) is measuring pain as a quality of life factor in its research.

Public attitudes towards pain have been explored in one study[176] which confirms anecdotal evidence that both patients and treating physicians influence cancer pain treatment in a variety of ways. More than half an interview sample of healthy adults in a US community reported major concerns about taking narcotics for cancer pain; most of them were concerned about mental confusion, development of tolerance, addiction and other undesirable side effects. Stiefel, studying medical personnel beliefs, found similar misconceptions albeit to a lesser degree but nonetheless leading to undertreatment of cancer pain. Smith et al in Australia found that less than 20% of new graduates in 1990 knew that radiotherapy was a technique for palliative pain control and only 18% knew that operative medical treatment for cancer was also a palliative pain control technique.

The working party in its discussion considered that a community wide education program on modern pain theories would be a public health promotion of great value. This campaign could support and build on the work of the pain management working group established by interested professionals in the ACT who have been exploring this issue for some time.

Stiefel[177] examining the psychosocial aspects of cancer pain has noted the need for therapeutic strategies that include assessments of personality, affect, cognition and behavioural responses. This model is already in use in some areas of chronic pain management in Canberra and could, with professional encouragement, be extended to include cancer pain management.

Psycho–social management

Psycho–social management is being discussed in a variety of ways in the literature. While this overview can be no more than a rough sketch some useful points may be made for strategic planning within the ACT. Both in the United States and Europe the management of psycho–social issues is now acknowledged as integral to effective patient care. Oncology social workers in Canberra already work within such a paradigm in cancer treatment; and with the recent establishment of the Cancerra Clinical School opportunities for multi–disciplinary clinical practice development could be further explored.

The concept of psycho–social management in oncology reflects the worldwide movement to re–examine the meaning of health. The Declaration of Alma–Ata (1978), sponsored by the World Health Organisation encapsulated what was becoming a social movement when it defined health as *'a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity'.*[178]
The Ottawa Charter, in 1986 building on the 1978 Declaration, reflected the growing sophistication of the public health movement in its statement that
"To reach a state of complete physical, mental and social well–being, an individual or group must be able to identify and to realise aspirations, to satisfy needs, and to change or cope with the environment. Health is ,therefore, seen as a resource for everyday life, not the objective of living.[179]*"*

Some theoretical perspectives

The relationship between social support and health spawned a large body of literature in the seventies and early eighties attracting the interest of psychologists, social workers, sociologists, anthropologists, and epidemiologists. However no unified conceptualisation of the meaning of social support or its role in health and health behaviour or indeed how it can be measured, has yet been developed.[180] [181]As this paper discussed in presenting health literacy concepts, the Nutbeam report described the categories of social support as being material, operational, informational, emotional and mental. Various studies have confirmed the correlation between outcomes of health and wellbeing and levels of social support. Theoretically, it still remains unclear whether social support in itself prevents illness or whether it acts as a buffer against stressful situations reducing their impact. For survivors of cancer, and those faced with a life threatening situation, adequate social support appears to be essential to an individual's capacity to cope on a daily basis.

A theory of cognitive adaptation was presented by S.E. Taylor in 1983 [182] after interviewing women with breast cancer and many of their family members. It was argued here that adjustment centred around three themes: a search for meaning in the experience, an attempt to gain mastery over the event in particular and life in general, and an effort to restore self-esteem through self-enhancing evaluations.

A public health psychology has also begun to build a body of knowledge that examines illness within its social context and relates the afflictions of individual people to the groups to which they belong or the environment in which they work and live. Social action theory described by Craig Ewart at John Hopkins University in the US in 1991,[183] draws together much of the work done in the field of public health psychology to that point. Public health differs from medicine, he asserts, in its social-contextual approach which has not only advanced the control of disease but has enhanced quality of life in ways not made possible by the clinical mode. He illustrates this in the history of infectious diseases where the early attempts to determine who became sick, and where and when, led to significant reductions in the prevalence of disease long before the biological mechanisms of these illnesses could be explained or modified. While the focus in this field is also on preventative health, such theoretical underpinnings as self regulation being an action state, the process of self change, the social environmental determinants of self-regulation and social contexts and stages of self-change all provide opportunities for theoretical insight with the cancer survivor in clinical practice.

Psychological conditions related to cancer have led in some places to the development of comprehensive therapeutic models of care.[184] Three underlying concepts have been extrapolated by Razavi & Stiefe[185] [186] from the current literature:

Stress: is presented as a psychological disturbance due to the consequences of a sustained stressful situation. Cancer presents the individual with a psychological challenge both in terms of adaptation as well as adjustment.
Survivorship provides a challenge to maintain an optimal quality of life for patients post treatment. Whether it be the haematological patient cured or the breast cancer patient post surgery, psychosocial factors are increasingly being taken into account in evaluating a treatment's success or failure.
Rehabilitation: includes specific support by a multidisciplinary team, in valuing engaging both psychoscocial and pharmacological interventions to improve the patients quality of life.

Existential psychology has been offering insights to the cancer experience since Frankl (1959) in his seminal exploration claimed that people attempting to invest meaning in their existence, actually ask the question what can they expect to give to life rather than what they can get out of life. Rollo May's concept of courage[187] is yet another illustration that Beck[188] uses in discussing existential concepts in rehabilitation. May expressed it thus:

> *'To live the life of self-expression requires courage. To love greatly, to admit one's hate without having it destroy one's equilibrium, to express anger, to rise to heights of joy and know deep sorrow, to go on far adventures in spite of loneliness, to catch*

> *lofty ideas and carry them into action – in short, to live out the infinite number of instinctual urges that rise in glorious challenge within one – this requires courage.' (page 193)*

Beck summarising the literature asserted that courage defined in the philosophical and psychological literature generally occurred in the presence of the following conditions:

a) a careful presence of mind and deliberate action;
b) the presence of difficult, dangerous, and painful circumstances;
c) morally worthy intention;
d) the person is engaged in an act that has existential meaning for him or her.

Without that existential meaning, daily efforts become nothing but the drudgery of the slave. While the concept is acknowledged as elusive and metaphysical, ordinary experience frequently acknowledges that for the person diagnosed and living with cancer courage is a quality recognised by those around them. Empowerment in a counselling setting encourages both an understanding of courage and how it is a measure of motivation to assist individuals when they find themselves overwhelmed by their experience.

A study by Lewis (1989)[189] using psychometric testing hypothesised that external attribution's of control and higher levels of experienced meaning protect self–esteem and reduce anxiety and when left unmediated by either externalised control or perceived meaning, the longer the experience with incurable cancer, the higher the level of anxiety and lower the level of self– esteem. She found that attributing meaning to their situation was a significant predictor of both higher self esteem and lower anxiety. However, neither externalised control or longer experience with cancer predicted levels of either anxiety or self–esteem.

What are the psychosocial issues for cancer survivors?

A 1989 literature review in the US [190]nominated the following:

- fear of recurrence and death;
- anxiety about losing close contact with the treatment team once therapy is complete;
- anger and depression related to physical compromise;
- alterations in customary social support following re–entry into "wellness role";
- increased sense of alienation and isolation;
- imprinting of the experience, affecting the patient's priorities in life and coloring new experiences;
- employment and insurance problems.

The consumer literature review undertaken by the NHMRC 's working party on the Treatment of Diagnosed Breast Cancer found the women's voice asked for particular treatment service models and approaches. No Australian research has to date explored psychosocial issues and survivorship.

While much work has been done in the literature to explore quality of life issues, the methodology rarely accounts for individual values as well as satisfaction[191].. Anecdotal evidence together with some exploration in the literature indicates that psychological and emotional meaning [192] reflected in the quality of relationships become important post treatment issues.

Information about emotional issues

The working party considered that the following information needs, which were generally identified as 'unmet' in the Canadian Cancer Society study, would be unmet to varying degrees in the ACT:

- Information about possible emotional reactions to cancer and to its treatment
- Information about how other people have learned to accept a diagnosis of cancer and to live with the fear of recurrence
- Information about the possible impact of cancer on personal and social relations
- Information about how to deal with lifestyle changes and with concerns about changes in body image
- Information about the availability of support services and mental health counselling for cancer patients and their families
- Information about how to deal with the emotional reactions of family members
- Information about the emotional impact of a recurrence of cancer
- Information about the emotional needs of patients and family members dealing with cancer in an advanced stage.

While services provided by oncology social workers do assist those patients with their emotional problems, there is no automatic referral for all cancer patients, nor is there any way of evaluating the level of unmet need. It was for such reasons that a systemic research project to evaluate psycho–social issues was recommended to the Reference Group.

The need for emotional support

The most common areas of concern for patients were:

- coming to terms with the fact that they have cancer
- living with the fear of a recurrence
- accepting the changes to their bodies and in their lifestyles that have been brought about by the cancer and its treatment
- dealing with their own emotions and with the emotions of family and friends

The Canadian Cancer Society study identified some groups in particular as more likely to express need for emotional support –women, younger people, people in remote locations and socially isolated people in large cities, people with leukaemia, Hodgkin's disease or lymphoma, people with advanced cancer. The timing of emotional support, its accessibility, and awareness of existing support services, (especially cancer support groups and the Cancer Society) were all identified as need areas.

The best form of emotional support is that provided by family interaction and social involvement with family and friends. Fear of dying can shadow a quality remission and the continuing exploration of what professionals in particular can do to address this need is an ongoing challenge.

The South Australian Carers Support Network has addressed this at a community agency level by developing a loss and involving work in group format to explore the issues.

The problem of unmet emotional need and social support

The stigma that once surrounded a cancer diagnosis has been substantially eradicated in white Anglo–Saxon middle class society. This is not generally true for traditional European, South American or many black African cultures and some Asian societies where a cancer diagnosis is considered still to be a death sentence.[193]

For the predominant Canberra population it is possible therefore to predict that some of the excesses of past stigmatisation – the fear of contagion, fear of death or loss, denial of illness – have been eradicated. Lack of knowledge about the causes of cancer and the possible cures were identified by Susan Sontag, in her essay *Cancer as a metaphor,* as the concerns people had about cancer. She compared the history of beliefs about tuberculosis in the last century with the beliefs about cancer still held by many today reflecting archetypal notions of good and evil.

The main problem for the Canberra community is its relative newness. Friendships are created through networks at the workplace and loss of or reduced employment means the loss of social contact and support. This is described in the literature as decreased activity and role changes. The effects of serious illness such as cancer and its treatments may prevent individuals from carrying out their usual roles and responsibilities. Role change can result in the loss of valued identities.

For those people who do maintain a work role the effort is such that at the end of the day there is no energy for the usual social activities. The literature confirms that the size of one's social network and the level of emotional support are correlated. Even the simple functions of visiting and being visited, shopping and doing small errands can reduce social isolation.. However a recent study exploring emotional support following cancer found amongst women that it was not so much the number of social contacts that were important as the woman's social functioning and the quality of her interactions with her family.

Bereavement services: loss and change

A number of issues have been identified as important in improving the quality of life of people with a poor prognosis and their families and friends. The need for education in understanding loss and managing change has been identified as an essential element of good social health. Complicated grief reaction and inappropriate social and psychological responses in various ways contribute to morbidity in remaining family members. This in turn is reflected in health demands in other parts of the health system. The palliative care working party considered the cultural diversity of modern Australian society is not reflected in the professional training programs around death and dying; and that the delivery of palliative care is still dominated by the Anglo–Saxon culture.

A community education bereavement project, funded under the national palliative care program is currently being developed under the auspices of the ACT Cancer Society together with the National Association for Loss and Grief (NALAG). Using the empowerment model – another illustration of public health practice – it is designed to enhance community understanding of bereavement issues. In this way it is hoped carers and families will be able to contribute to the quality of life of a person living with a poor prognosis by better understanding the psychological steps to separation. And indeed for all to understand and accept that dying is a social act.

The project objectives are to
- develop a continuing education program for health professionals and community workers
- provide training for carers and volunteers
- develop a support program for families and children
- develop a broadly based community education program on death and dying.

The project will be managed by a representative group in the area including community agencies and ACT Department of Health and Community Care and consumer representatives.

A Professional Reference Group comprising social workers, grief counsellors and community educators will act as the expert body to a series of design teams who will undertake work to achieve the above objectives, targeting the following:

- children diagnosed with cancer
- families and children of cancer patients
- professionals working in the field of palliative care
- carers and volunteers
- the general community

Employment and financial issues

Employment problems:

No research has been undertaken yet in Australia around the employment issues for tho receiving cancer treatment. Private insurance sickness policies don't enable a graduated return to work. Razavi et al found in examining the professional rehabilitation of lymphoma patients that only 54 % had returned to work.[194] The study did not indicate the underlying factors in the low rate of return to work, but found high levels of anxiety and depression in those who had not returned to work.

Anecdotal evidence from social workers in Canberra indicates couples in small business, people on contract employment, or who work casually can have particularly heavy financial pressures. Chronic illness for those in small business can create unsustainable, financial and physical pressures; part-time and contract workers can have difficulties maintaining their employment either during and/or after the treatment phase. For those who do maintain their jobs, earning sufficient on reduced hours to meet such commitments as the house mortgage can lead to increased debt and further pressures. The conditions of permanent public servants whose sick leave accrues and who therefore are financially cushioned during a period of illness compared to those nominated above who find debt accruing instead can lead to marked differences in quality of life post treatment. However once accrued sick leave ends, public servants can find themselves with the same financial pressures and caught in the poverty trap of the social security system.

Income support policies.

The Canadian survey found that employment and financial problems seemed to affect between 15% to 25% of the people with cancer surveyed. While for most the impact was not severe, it was associated with an increased level of distress and a decreased quality of life.

No such survey has been undertaken in Australia. However, anecdotal it is recognised that the poverty trap of the social security system can create substantial pressures for people with a chronic illness and most especially those living with a poor prognosis. The additional psychological and emotional adjustments for people who have been economically independent all their lives is magnified in the current delivery of social services. The assistance received often appears to be unsympathetic and unresponsive to the medical requirements of patients. The long wait in lengthy queues, the noisy office, the many forms that can need to be completed with frequently more than one journey required to the nearest office; all reflect a lack of understanding of social health issues in our health and community care system. Canberra cancer specialists however have been particularly helpful in assisting social workers fast track patients through the system by filling out the appropriate disability forms, enabling most to obtain income security a little faster by not having to wait to see a Commonwealth Medical Officer.

The working party recommended that the Commonwealth Department of Social Security give serious attention to the need to train some counter staff to sensitively deal with the circumstances surrounding a cancer prognosis and assist with courteous processes such as making appointment times rather than forcing people into waiting in queues at a time when their general health is poor.

The Social Security Review 1986–1989 identified three policy objectives for reform at the time:

- redistribution, or equity in allocation;
- adequacy and uniformity of payments;
- linkages between income support and employment, education and training programs.

Professor Bettina Cass who directed the review exploring Social Security Policy into the 21st Century[195] has recently posed the question relevant to cancer care when she asked: *'how can caring work be better recognised in social security policy?'*

Issues to be addressed include the current categorisation and structure of the system of pensions and benefits, adequacy of payments, eligibility and income–testing using the married couple as the applicable unit and the structure of income tests for those working and receiving benefits.

A British proposal for an extended 'basic income' is worth exploring. The conditions for payment would not only be based on criteria related to paid work but on a wider definition of *social contribution and participation.* Such an integrated payment

> *'based to a much greater extent than currently on the individual as the unit of assessment, would emanate from the clear societal understanding that these recognised forms of social participation and contribution to the economic and social welfare of the community provide eligibility for income support. Such support would be provided equitably, so as to enhance dignity and to support participation.'*[196]

Such a proposal requires a debate about the Australian tax system and its capacity to raise sufficient revenue to support such a wide-ranging reform. Julia Perry, in a discussion paper prepared for the Department of Social Security, explores the application of such a concept.

> *'While there are theoretical attractions to more radical approaches such as basic income and a guaranteed minimum income, it is unlikely that these would fit the present framework of community values, nor the Government's fiscal objectives.*
> *The existing multi-payment system has advantages in that for recipients it targets the rate of payment according to need, which promotes adequacy and horizontal equity. It recognises the right of specified groups to be supported outside the labour market while encouraging others to improve their prospects of self-support. The income test enhances vertical equity and restrains outlays. It allows Government to control access to income support to avoid incentives to rely on public assistance for people who have other choices.'*[197]

However she goes on to indicate there are a number of disadvantages in the current system, amongst them being gaps in coverage and assumptions for recipients which can be both inappropriate and stigmatising, and which lead to differences in treatment. The current system is complex, not always sensitive to the circumstances of individuals and does not easily accomodate changes in individual circumstances.

Ms Perry proposes a conditional guaranteed income model which would retain the advantages of a variable rate, means-tested and activity-tested while addressing the disadvantages of the present system. These policy issues have direct application to the financial security (and hence quality of life) of cancer survivors, and the carers of those whose condition is terminal. The paper identifies a number of obstacles in moving from the current system and she identifies strategies for doing so. Both Perry and Cass acknowledge the need for further community discussion and an exploration of social attitudes.

Perry's discussion paper points the way to a gradual acknowledgment of the changing social situation in Australia .The Conference of Commonwealth/State ministers for the Status of Women, in a paper titled *The Price of Care,* has also begun to explore the need to improve community awareness about caring responsibilities and to see a *'better appreciation by governments of the social and economic benefits of unpaid or underpaid work by carers and greater acceptance by employers of the relevance of more flexible working conditions and more generous attitudes to requests for leave.'*[198]

Financial issues

- drugs and supplies
- prothesis and wigs (in some cases)

- medical equipment and devices
- child care
- superannuation anomalies

A range of, sometimes substantial costs may be incurred by patients, depending on the type of cancer care. What in real terms can this mean for the ordinary patient? A social worker told the story of an older woman on a pension who in a review visit in autumn to her medical oncologist, sought a new prothesis having had breast surgery only to find that the budget in this area was out of funds and rationing meant 'prioritising' services until July. A young family man with end stage disease who had received much medical treatment for over ten years found, in late summer when he wished to be able to picnic by the lake with his children, that funds for the portable oxygen he needed were not available and the social worker needed to seek emergency finance from a local club to provide him with the support.

Need for review of oncology social work service delivery

The working party discussed the issue of emotional support and recommended that the current social work service examine the problem of systemic identification of psycho–social need in order to assess its extent.

It was also recommended that the service models of oncology social workers should be analysed to enable a re–examination of service delivery away from the case–model approach and various alternative innovative approaches be explored while ensuring that one to one or family counselling continue to be employed where necessary.

Such a review would at the same time provide an opportunity for service agencies in the community which are in constant crisis mode because of the overwhelming level of unmet emotional need in the community. The City's agencies consider that the referral patterns for psychological, social and practical support are not working effectively. Anecdotal evidence points to 'closed book' syndrome in this field whereby social health problems that cannot be met are dealt with by simply not providing a service.

Community participation

Community participation has been a major motif in this report. The empowerment literature provides a rich field of potential insight to cancer care and management. Most of the research has been undertaken in the areas of public health and social work and in general has not explored the application of empowerment models to clinical care.

Wallerstein[199] in reviewing the literature defines three distinct aspects of the term:

- psychological empowerment merges the intrapsychic concepts of self–efficacy and motivation to exert control with actual skill development and participatory behaviour through collective action.

- organisational empowerment arises from democratic management theory and refers to those organisations which develop and exert influence in the larger community to promote system-level change.
- community empowerment refers to communities achieving equity in resources, having both equity and the capacity to identify and solve problems, increasing the effectiveness of natural helping systems and having a sense of neighbourhood and community.

Interested consumers, in particular those involved in the Oncology Services Consumer Group, together with some professionals, consider that cancer care and management with a rapidly ageing Canberra population will need to harness all three aspects of this approach if equity and access are to be maintained.

Projects like the recently funded Community Education Bereavement Project (see page 73) enable cross fertilisation between various professional groups and the community to continue to develop an innovative approach to such issues.

Zimmerman [200] [201] developing a structural model analysing participation and empowerment has constructed a theory of learned hopefulness which proposes that empowering experiences can provide individuals with opportunities to learn skills and develop a sense of control in debilitating situations. This theory converges to some extent with the literature on the benefits of self-help groups, informal care and self-care. Dean[202] saw the opportunity for self-care to redress the alienation of the increasingly technical specialised health systems that have developed to respond to illness. The emerging trend of chronic disease and patient alienation is finding its voice in the consumer movement. Key research questions remain to be answered in regard to self-care; amongst them being the extent to which our knowledge of self-care contributes to understanding the processes that maintain health. It was noted that surveys dealing with self-care behaviour in representative samples of populations and clinical trials of self-care interventions are rare. Methodologically rigorous longitudinal studies are virtually non-existent.

Research program

Cancer patient satisfaction with care is an issue that clearly needs further research. A study, undertaken by Newcastle University's Faculty of Medicine, found that while patients were satisfied with the opportunities provided to discuss their needs with doctors, and the interpersonal and technical competence of doctors, few were satisfied with the provision of information concerning their disease, treatment and symptom control and the provision of care in the home and to family and friends.[203]

Researching the needs of the Australian cancer survivor is an urgent project. The systemic issues of psycho-social need appear to be an element of care overlooked in the main. Qualitative research that asked those living with cancer what were their perceived challenges could be an appropriate place to begin. The analysis of data from the Care Continuum and Health Outcomes Research Project will assist in an understanding of current service utilisation in the 6 - 12 months post hospital discharge.

Rehabilitation and Extended Care working party recommendations

Rehabilitation and Extended Care working party recommendations

Medical management

1 A more appropriate hospitals admission policy for those cancer patients requiring readmission while undergoing outpatient treatment be dealt with as a priority. This request has already been made to the hospital administration by the Oncology Services Consumer Group.

2 The needs for improved case management be explored by a task force with leadership provided by the Division of General Practice with a view to developing a continuous professional education program.

3 A community wide education program on modern pain theories be undertaken as a public health promotion.

Psycho-social management

4 The needs of patients living with cancer be explored within the ACT through a Needs Analysis Survey.

5 The psycho-social needs of patients be comprehensively addressed before hospital discharge and a formal pathway of referral be developed.

Community services planning and support

6. A bereavement education strategy be undertaken on an area wide basis to improve community access to grief and loss support services.

7. The problem of unmet emotional need be explored through a systemic identification of psycho-social need in the Canberra population.

8 The role of the carer be seen as integral to good patient care.

9 The increasing demands being placed on the non-government sector with changes in health policy be evaluated through a planning process undertaken by the ACT Department of Health and Community Care.

10. This planning be supported by the development of a data collection system identifying the special needs of cancer patients for community support services.

11. The opportunities for General Practitioners to be involved with community agencies continues to be encouraged by the Division of General Practitioners.

12 The special needs of migrants and Aboriginal Torres Strait Islanders be addressed concurrently with the above recommendations.

13. The role of the Oncology Services Network be acknowledged and it be encouraged to oversee the provision of an education forum on cancer matters for community agencies.

14. Education programs about the special needs of cancer patients are required for coordinators and support staff of community agencies (targeting in particular the Department of Health and Community Care agencies with open forum case studies as an example.)

Commonwealth administrative and policy issues

15 ACT Department of Health and Community Care recommend to the federal government that the guidelines be expanded to include convalescent care for palliative care clients of all ages.

16 The Department of Social Security address the special needs of cancer patients through in service training of counter staff.

17 The Department of Social Security develop a more appropriate appointment protocol to for cancer patients.

18. A national policy review be encouraged to explore flexibility around the insurance/superannuation needs of seriously ill people.

Project Discussion

The concept of the cancer survivor has not entered the professional lexicon to any great extent in Australia. The person living with cancer has a variety of psychological frameworks to draw on to make sense of his or her experience. Some come from family and friends, some from the culture or sub–culture within which they live, still others from their reading both of an informed and popular kind.

In terms of health needs, this point of the care continuum is the one most ignored. Indeed some health economic models in Australia leave it out altogether in their conceptualisation of health costs. The issues for research exploration cover a wide field – from preventive health practice to appropriate preparation for palliative care. Healthy survivorship of cancer is undoubtedly influenced by the effectiveness of the treatment process. For those who felt they maintained their autonomy, exercised full choice about treatment options and obtained emotional and psychological support from professionals, family and friends, the chances of ongoing morbidity.

However, if an individual already has emotional/psychological and social/financial problems (most of us some of the time) or diagnosis is given in such a way as to induce a post traumatic stress syndrome then autonomy and independence are already compromised before treatment begins. If these problems are not acknowledged or poorly attended to, then the treatment process becomes exaggerated and cumulative "morbidity" builds up. Loss of self esteem and anxiety, depression are among the symptoms that can present. Assisting the individual to deal with an experience that can rapidly overwhelm is the key to quality survivorship. None of the above has described the range of physiological and pharmaceutical complexities that beset the individual experiencing cancer treatment. That we are discussing survivorship presumes they have indeed come through the medical experience. 'At what cost?' is what the individual sometimes asks.

Those who provide services need to revisit that question in partnership with their patients. From the beginning of the experience following the shattering news of a cancer diagnosis, the individual needs a reference framework for which most have not prepared.

In planning the provision of services – program planning – three distinct groups of patient need must be addressed:

- first, the immediate medical and psychosocial needs of patients in the first one to three years post treatment.
- second, the needs of cancer survivor who are moving towards the five year 'cure' but still require monitoring and some medical, emotional or psychological support (for example, if another family member/friend is diagnosed with cancer).
- third, the needs of those patients who have lost remission, but still have good quality of life, are aware that no cure is possible and no further active treatment is available but do not yet need palliative care.

<u>Cancer rehabilitation program</u>

Rehabilitation of the cancer patient in the ACT is ad hoc and no coordinator is provided to develop a case plan nor do cancer patients in general obtain services from the Rehabilitation Unit of the hospital. Professional members of a cancer rehabilitation team can include a physiotherapist, occupational therapist, speech pathologist, maxillofacial prosthetist, psychologist, social worker, vocational counsellor, and might include as well psychiatrist, dietician, enterostomal therapist, dentist, dental hygienist, chaplain, sex therapist and oncology nurse. Kurtsman recommended that team meetings should ensure appropriate referrals to outside consultants and either a trained psychiatrist, or an oncology nurse or social worker should be team coordinator, to develop and ensure a comprehensive plan is developed.
No such program has yet been discussed within the ACT.

The ACT (and most areas of Australia) cannot be said to have comprehensive provision of cancer care at this point in time. Comprehensive cancer treatment, as many references in this report have already made clear, involves multidisciplinary care, which spans not only various aspects of the medical team but also the involvement of the allied health team, nursing, social work, physiotherapy, psychology, nutrition and occupational therapy. While these services are provided they are not integrated into a comprehensive model of clinical practice. Development of clinical audit where the opportunities for intellectual sharing and professional development can be expanded beyond the narrow professional streams of each discipline is now the recommended approach in many cancer care settings around the world.

Pain

Anecdotal evidence about the response to pain is similar across Australia. Many people believe the myth that stoicism is helpful to pain and consequently do not even take analgesics let alone opiate derivatives which they believe are addictive. This continuing ignorance of the general population and some areas of nursing and medicine creates much needless suffering. Given the already acknowledged problems of medical education in Australia and the lack of professional leadership for community based practitioners the working party's concerns appear well placed.

Research program

An identification of the rehabilitation needs of cancer patients needs could be undertaken through a specially designed project that examines the current provision within the contex of a model program using patient needs analysis. Research data from the Care Continuum & Health Outcomes Project being undertaken by the Epidemiology Unit in the ACT Department of Health and Community Care could in time assist in identifying the current utilisation of cancer services and the extent of unmet needs.

The need to explore intellectually the issue of social support in a city such as Canberra is probably more urgent than in other more established communities. Just what do people living with cancer in Canberra need in regard to appropriate and adequate social support? This question cannot be answered with any kind of professional certainty at present.

Palliative Care

Goal: To develop a business plan for palliative care services in the ACT.

Outcome: The group represented all agencies providing palliative care for cancer services within the ACT which met nine times between February and May 1995. The group examined the objectives of the area health management program and all recent reports undertaken in house and though consultancies examining service provision in the ACT or highlighting current deficiencies. The major effort of the group was in developing the Business Plan outlined below. This involved all of the membership writing together, reading prior to each meeting the drafts as they evolved and agreeing within the meeting to the changes nominated after frequently quite spirited discussion.

Profile of current services:

Service provision comprises medical, nursing and supportive care. These levels of care are provided in all three hospitals, with Woden Valley Hospital providing acute palliative medical care.

Nursing care is provided both within the hospitals and through the Home Based Palliative Care Program which was established by ACT Community Nursing Service in conjunction with the ACT Hospice Society . While modelled on the Western Australian Silver Chain service it differs from it in not having a medical practitioner attached to it. This lack of specialist medical leadership has weakened the provision of comprehensive palliative care in regard to the rapidly expanding area of pain management and medical palliation.

Psychosiocial support is provided within the institutional setting by social workers at Woden and Calvary Hospitals and the ACT Hospice. Counselling support for community services is also now available through the Home Based Palliative Care Program .

Social support within both institutional and community settings is provided by a large network of trained volunteers under the auspices of the Hospice and Palliative Care Society.

Palliative Care key issues identified

Appointment of a medical palliative care director

Accessible palliative care services

Effective service provision

Improved health care for persons with far advanced disease

Development of a seamless service delivery

Identification of health needs

The Palliative Care Services Consultant Report of November 1990[204] made the following comments:

> *'While there was great concern expressed about the need for hospice beds, the focussing of interest seemed to have diverted attention from many other issues of importance in the establishment of a comprehensive palliative care service, and the consultants were surprised that relatively little appeared to have been gleaned from interstate or overseas experience in the field, or from the available literature.'* (Redpath & Maddock).[205]

However research currently being undertaken should assist in breaking down the regional isolation and enable the ACT health system to develop a comprehensive picture of palliative care health needs over the next 12–18 months:

The Care Continuum and Health Outcomes Project (CCHOP) under the direction of Dr Bruce Shadbolt, epidemiologist, is a cohort study investigating the care continuum and health outcomes of approximately 8,000 inpatients (approximately 1,200 cancer patients) and their experiences prior to admission, during their hospital stay and to six months after discharge. It covers formal and informal service utilisation, costs across the care continuum, health outcomes including quality of life and explores cost–effectiveness models to improve the use of resources. This study is being funded by the Commonwealth Department of Human Services and Health.

The Care Continuum and Quality of Life project is a sub–study of the CCHOP and is being funded by the National Palliative Research Program. This study is under the direction of Dr Paul Craft, Medical Oncologist and focuses on palliative cancer patients, with an expected sample of 200–250 people. In addition to quality of life issues and the types and coordination of care, it will also determine the quality of information provided by health professionals and others to patients and their carers, including identifying deficiencies. Finally it is anticipated this study will contribute to the identification of a minimum data set.

Population profile data

To effectively monitor the cancer palliative care needs of the ACT it is necessary to know the number of persons who die of cancer in the ACT and where they die.

The Australian Bureau of Statistics publishes the number of usual residents of the ACT who died of cancer as well as registered deaths in the ACT. 'Usual resident' deaths are just that. If a person whose usual residence is the ACT dies in another state, death is coded as having occurred in the ACT. In contrast, 'registered deaths' are the deaths of persons who actually die in the ACT but may live somewhere else, for example a person from Braidwood who dies in Woden Valley Hospital. The place of 'registered death' is probably a more useful policy and decision making tool for predicting the use of ACT palliative care services.

The actual place of death is recorded on the death certificate for example, hospital or a person's home. However, this information is not freely available from the Registrar of Births, Deaths and Marriages because of privacy considerations. This data needs to be collected and readily available for informed service delivery. At present palliative care data is based on number of occasions of service rather than number of people being serviced. Although number of occasions is useful in the short term, it is difficult to extrapolate future needs by this method.

What is palliative care?

The United Nations defines palliative care as:

> *'The total active care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anti-cancer treatment.*
>
> *Palliative care:*
> - *affirms life and regards dying as a normal process;*
> - *neither hastens nor postpones;*
> - *provides relief from pain and other distressing symptoms;*
> - *integrates the psychological and spiritual aspects of patient care;*
> - *offers a support system to help patients live as actively as possible until death; and*
> - *offers a support system to help the family cope during the patient's illness and their own bereavement."*
>
> *Radiotherapy, chemotherapy and surgery have a place in palliative care, provided that the symptomatic benefits of treatment clearly outweigh the disadvantages. 'Investigative procedures are kept to a minimum.'*

The working party endorsed this definition. Continuity of care is an essential aspect of palliative care. A Report[206] prepared by a palliative care working party in New South Wales in 1993 provided a set of principles which with minor modifications, was adopted by the ACT:

Principles for the provision of services delivering palliative care

- **Accessibility**
  Palliative care should be provided to all patients suffering severe symptoms from advanced disease. Care should be available so that all avoidable suffering is avoided.
  The working party acknowledged that this is probably still not occurring in the ACT and that strategies are needed to ensure access to both primary providers of palliative care as well as consultant palliative care services.

- **Effectiveness and efficiency:**
  Health services have a responsibility to ensure their services are effective and efficient in meeting the goals of palliative care.
  The NSW Report highlighted the lack of any basic comparative data to make such assessments – the working party considered that the development of a business plan is an appropriate beginning.

- **Quality:**
  Measurement needs to be population focussed to ensure that the target population is receiving a high quality service. The contribution of the carer, family and other informal sources of support to high quality care needs to be recognised and addressed.

  Both quality assurance programs and peer review need to become an integral part of the activities of a palliative care service. Academic leadership through the ACT Clinical School in conjunction with relevant leadership in other academic institutions for a multidisciplinary approach is seen as necessary to developing high standards of care.

- **Integration:**
  Palliative care should be part of mainstream health care.
  This requires integration between palliative care services in the community, the hospitals, the hospice, and nursing homes. These are collaborative, networked as well as formally established. They include the medical disciplines of medical/radiation oncology, surgery, HIV/AIDS, geriatrics and rehabilitation together with nursing, social workers, physiotherapy, hospice volunteers, and community service agencies.

- **Continuity of care:**
  Multi–modal approaches to therapy can mean loss of continuity of care. The role of the General Practitioners needs to be maintained and strengthened and the issue of case management of medical and psycho–social needs has to be addressed.

- **Appropriateness:**
  Appropriate services recognise the intrinsic dignity of patients with advanced disease and their entitlement to self determination and involvement in their care.

  To do this a comprehensive assessment of the patient's needs, goals and preferences, and those of his/her family must be made and this may require the delivery of multi-disciplinary team care. Services need to be culturally sensitive, and responsive to the special needs of children, Aboriginal people, and people from non–English speaking backgrounds.

ACT Palliative care services business plan

Goals	Targets	Strategies
1. Improve the health care of patients with advanced disease		
Promote the quality of life of the patient who is dying	No persons should die with uncontrolled symptoms. No persons should die without access to social, psychological and spiritual support To minimise avoidable suffering in patients with advanced disease. To achieve the best possible quality of life for patients with advanced disease.	Improve the skills of relevant health care providers in the care of the patient who is dying Provide appropriate carers services (see goal 3) Include quality of life measures in audit and review processes of the person who is dying Promote good decision making and symptom control in palliative care Define quality of life to include recognised measurements and regular patient surveys.
Improve autonomy and quality of life by maintaining the patient at home as long as appropriate	To provide and plan for appropriate primary care and community consultative services to facilitate care at home in 1995 and towards the year 2000. To provide Home Help Respite Care and paid care for people who require it.	Obtain annual epidemiological profile of death from cancer patients Obtain separate data on acute admissions for palliative Care to Woden Valley Hospital and Calvary Public Hospital Monitor length of stay in last 100 days of life and rate of readmission 7 days before death Monitoring of the Home Based Palliative Care Service, ACT Hospice, Respite Care, and palliative care services of Calvary/John James Private Hospitals.
Facilitate normal grieving and minimise complicated grief	Improve community education about the normal grieving process along the care continuum Improve the emotional health of patient, family members including their children and other carers.	Provide educational programs for volunteers and carers, professionals, family members including children. Establish appropriate services to provide the necessary support for the patient and carer/family especially in the last phase of life Develop programs that are sensitive to culture and gender. Detect and refer complicated grieving appropriately. Provide a professional and educational program for cultural understanding of death and dying identifying in particular the different grieving responses amongst Aboriginal and Torres St Islanders and migrant groups.

To address the specific needs of children both as patients and as family members.	Improve the emotional health of patient, family members and other carers.	Identify current resources for bereavement and grief counselling and support within the A.C.T. and ensure appropriate access is facilitated. Identify gaps in service provision to paediatric oncology patients and their families Undertake a research program to determine the psycho-social *impact* of • the death of a child from cancer and other illnesses on parents, siblings, and extended family. • grief and loss on professionals, other carers, and the child's social network.

2. Ensure the availability and delivery of appropriate services to patients with advanced disease and their carers.

Facilitate the role of GPs and community nurses as primary care practitioners	Referral to a palliative Care service is available from local practitioner Ensure that GPs and community nurses respect the individual patient wishes in regard to the range of services they may request.	Develop effective links between GPs and palliative care services, hospice and acute palliative care . Ensure there is knowledge of the range of services to facilitate community care.
Establish/enhance access to multi-disciplinary palliative care services in the community by patients with advanced disease.	Ensure all persons dying of cancer are offered and obtain multi-disciplinary palliative care services.	Survey community need to ensure objectives are met. Provide an appropriate mix of services in both community and impatient facilities. Develop service provision in those areas of the community services that are currently not provided. Ensure that the ratio of bednumbers to target groups is maintained at optimum levels in specialised palliative care areas.
Ensure continued access to palliative care in the community on a 24 hour basis.	To minimise hospital/hospice length of stay in the last 100 days of life.	Provide after hours emergency services relevant to palliative care. Ensure palliative care patients obtain direct admission to the specialist palliative care areas when hospital admission is required.

3. Ensure that services are efficient and effective in the provision of palliative care

Provide high quality palliative care efficiently to all those requiring it	Appoint a full time medical director of palliative care	Ensure duty statement of Palliative Care Director reflects the needs of an area wide service model of palliative care.
	Improve the quality of palliative nursing care in hospitals and community	Recruit person with demonstrated palliative care experience and background in Oncology together with administrative and research skills to the position already established.
	Improve the availability of high quality social work services.	Appoint clinical nurse consultants in palliative care.
		Determine the appropriate case load level.
	Improve accessibility to appropriate services	Review of admission criteria to home based palliative care to ensure cultural sensitivity Ensure that regular reviews of admission criteria in institutional settings are undertaken
	Ensure that services provide for cultural sensitivity, patient rights and choice and the needs of the socially vulnerable.	Develop a multi-lingual brochure to inform the Canberra community of the range of palliative services provided
	Ensure optimum continuity of care between institutions and the community.	Develop a quality review process to ensure highest standards of palliative care.
	Improve the level of knowledge of health service providers throughout the ACT with regard to palliative care.	Develop professional education programs for medical, nursing, and allied health staff.
Ensure that appropriate support services are designed and integrated into the provision of palliative care.	Measure community needs for support services	Audit waiting times for current support services
		Survey current service use by the consumers and carers
	Development of a strategic plan identifying combined health and community care support service provision	Undertake a high quality research investigation into the needs of the community in regard to support services
	Ensure funding of community services reflects the changing epidemiological profile of the ACT and surrounding region.	Ensure that the planning process has a high level of consumer participation.
Seek to establish a centre of excellence for palliative care services.	That positions be established for training in palliative care across the disciplines.	That a working party be established to develop in conjunction with relevant tertiary institutions an appropriate curriculum.

Purchaser/provider model: its potential application for palliative care.

The Business Plan implicitly assumed an overall regional Palliative Care Service involving all agencies in its service delivery and an integrated model of service provision. However, since this project began, government policy has introduced purchaser/provider separation. The following is a brief discussion of the implications. A more detailed discussion is provided in the fourth section of the Area Health Program. The purchaser/provider model of palliative care theoretically would identify which of the hospitals provided palliative care more efficiently and encourage competition. It could also encourage the provision of more than one community based nursing service and multiple community support programs.

The beginnings of a purchaser/provider model of palliative care could encourage clinical audit to become part of agency practice in both medical, nursing and supportive care functions. The purchaser would begin by determining the extent of palliative care needs in the ACT. While the numbers who died are available, the extent of their palliative care needs still has to be addressed. Such information enables the government to undertake its financial and performance audit function to assess whether palliative care funds have been allocated efficiently.

Difficulties in implementing

The single biggest problem in developing a purchaser/provider model in palliative care at present is the substantial dependence state governments have maintained on federal government resourcing for this activity. Core funding within state budgets is problematic around Australia. The aim of federal funding in 1988 was to identify need which it successfully has. State governments, however, have yet to delineate palliative care as core business activity. With the ageing of the population, this is becoming a matter of some urgency.

Diagnostic Related Groups do not include a palliative care in their descriptive categories, thus hospital information systems are unable to discriminate between for instance adjuvant or palliative anti–cancer treatment'.

Clinical audit in palliative care

National leadership for medical audit was provided in the UK by the publication of a White Paper *'Working for patients'.* Because holistic multiprofessional care underpins the philosophy of palliative care programs the separate medical and nursing audits[207] which had begun in the field have in a number of instances been replaced by clinical audit, defined as

'the systematic critical analysis of the quality of clinical care including the procedures used for diagnosis and treatment, the use of resources and the resulting outcome and quality of life for the patient. Clinical audit is like medical audit but involves all professionals and volunteers, rather than only doctors.'[208]

Higginson describes audit as a cycle where standards or goals are set, compared with reality by observing practice, then results fed back to improve practice and set new standards and repeat the audit cycle.

Benefits of audit:

- identifies problems in practice;
- focuses staff time and resources on aspects of care which work;
- prospective audit encourages systematic assessment of patients and families in care
- by becoming part of the clinical routine helps most patients and families rather than examining a few 'special' cases.

Audit is important for education and training because the structured review allows analysis, comparison and evaluation of individual performance; promotes adherence to local clinical policies and offers opportunity for publication of results. Education programmes can be constructed to meet the demonstrated needs of individuals or groups. Audit may also be required for the recognition of training posts...'.

The standards that follow are already in place in its palliative care services. Two audit measures are outlined to illustrate options for practice. The information giving questionnaire that has been designed for the Palliative Care study currently being undertaken in the ACT could also be a useful audit instrument together with the broad range quality of life instrument (SF36) being used in the study. Evaluations of their reliability and validity for such functions will be part of the final report given to the Commonwealth in 1997.

Core standards

Core standards for palliative are:[209] (the following outline was developed by the Trent Hospice Audit Group in the UK)

Standard no 1: Collaboration with other agencies

Standard statement: There is effective collaboration with other agencies, professional and voluntary providing continuity of care and support for patients, and their carers.

Standard no 2: Symptom control

Standard statement: All patients have their symptoms controlled to a degree that is acceptable to them, and achievable by multidisciplinary team intervention within current palliative care knowledge.

Standard No 3: patient/carer information

Standard statement: The patient and his carer/s have the information they seek, relating to diagnosis and progress of disease, care options, and allied support services available to enable them to make informed choices.

Standard No 4: Emotional support

Standard statement: The patient and his carers have access, in confidence, to expertise in counselling, psychological and spiritual care, to provide emotional support.

Standard no 5: Bereavement care and support

Standard statement: The carers of the dying person have access to bereavement counselling information, and support services, including external agencies.

Standard No 6: Specialist education for staff

Standard statement: Specialist knowledge gained through courses, work experience and seminars is kept up to date within the multidisciplinary team, and disseminated to other professionals.

Audit Methods:The Edmonton Symptom Assessment System (ESAS)[210]

Bruera and Macdonald remind us that more than 50% of patients with a diagnosis of cancer will die of advanced disease, and many of them suffer from a variety of devastating symptom complexes.

ESAS has been developed to provide an assessment of different symptoms and for fast interpretation of the results to ensure benefit to the continuity of patient care. The tool consists of nine visual analogue scales (VAS) which include pain, shortness of breath, nausea, depression, activity, anxiety, well-being, drowsiness and appetite. It is considered now that the patient is usually the best judge of the symptoms they experience and they are therefore asked to complete the list drawing a mark along a 100mm line of the VAS. The form is filled out twice daily. Research undertaken to test the instrument included testing for its reliability and validity which have been demonstrated.

The current uses of such a tool are seen as the following:

- *Co-ordination of care between different physicians and other disciplines*
  ESAS scores improve continuity of care by standardising symptom assessment which allows both community and institutional referral to speak a common language and monitor therapeutic interventions accordingly.
- *Quality control*
  The baseline assessment provides a measure of severity of symptom distress in patients admitted to the palliative care programme. Follow-up assessments allow staff to evaluate effectiveness of different treatment interventions. Patients with good symptom control can be assessed for discharge planning; patients who die in poor symptom control require a review in order to establish possible causes and to plan for future similar cases.
- *Education and research*
  Education of physicians and other health professionals is helped by the presence of an ongoing assessment system. Students who need to quickly become familiar with many patients can follow ESAS to explore symptom complexes and understand the relationship between them. Bruera & Macdonald cite the literature to indicate that teaching rounds and case reports are greatly assisted by the availability of accurate data

Future Work: the instrument needs to be established in more patient populations particularly in non-English speaking patients, those impaired by significant or affective disorders. Correlation between different symptoms and the relevance of these on the patients overall sense of well-being needs to be better established. Significant variable such as overall opiate dose, functional performance of the patient and the level of social support are currently not assessed; but it is planned to continue to refine the instrument . The community schedule developed by Higginson, The Support Team Assessment Schedule (STAS) already does measure these variables the authors noted.

Audit method: The Support Team Assessment Schedule (STAS)

This instrument has been designed to examine the outcomes of care provided by community based support teams who work with cancer patients in the community in the UK. The instrument was designed in close collaboration with those working in the field and the measure of outcome was firstly clearly defined and agreed by defining goals. Having defined the goals, they were converted into measures which ultimately included the following 17:

Items in the support team assessment schedule

Ten patient and family items	Seven service items
Pain control	Practical aid
Symptom control	Financial
Patient anxiety	Wasted time
Family anxiety	Communication from professionals to patient and family
Patient insight	Communication between professionals
Family insight	Professional anxiety
Spiritual	Advising professionals
Planning	
Predicability	
Communication between patient and family	

Each of the items is graded 0 –4 and can be recorded regularly on patients during care. The results of the use of the schedule to date indicated areas where care was effective e.g. control of pain, and also where care was less effective e.g. spiritual assessment and the alleviation of dyspnoea and family anxiety. Feedback to the five teams involved enabled new practices to be initiated which are being audited.

Project Discussion

Palliative Care in the Community

Palliative care in the ACT has been well developed in the community nursing and supportive care areas although it lacks having its own specialist medical consultancy service. Neither is there any formal ongoing professional education to enable service providers to evaluate their care within a rapidly changing field. Despite the interest and commitment of those working in this area these two weaknesses are diluting the very considerable efforts that have been made to develop palliative care service delivery.

Hospice care

The recent establishment of the ACT Hospice has provided a focus for palliative care and immeasurably enhanced patient choice. However, it has been noted in the literature that stand-alone hospices can be expensive to administer and it maybe that justification for this will require integrated community services, as has already begun thus enabling Canberrans the opportunity to understand death and dying as a social experience.

Resource Management

The development of an interagency Business Plan for Canberra palliative care services was a major achievement. There has been a tradition in the past of using opaque decision making processes to determine resource allocation. From a service provision perspective this has not been conducive to good team building at either the inter-agency level or the inter-departmental level.

The working party which met on a number of occasions had high hopes of obtaining an outcome focus and sought to ensure there would be an integrated strategic approach to its deliberations.

The aim of the group was therefore to develop a Business Plan which would in a concrete and practical way spell out what is needed for the management of palliative services within the ACT. The membership of this committee involved all those working in the field of palliative service provision (see Appendix A.).

The departmental restructuring that occurred during some of this period resulted in the resource and planning areas unfortunately moving away from the strategic intent of these efforts and back to an individual agency focus. As a consequence there is a likelihood that overlap and duplication will continue to plague this area and handicap the development of an integrated multi-disciplinary palliative care service. The purchaser/provider model, if carefully developed, could provide another approach to effective resource management in palliative care.

Professional Education

Overcoming intellectual isolation in ACT health service provision is another challenge – a plague for all regional services. No coordinated clinical conference planning and formalised case presentations have yet evolved to enable ongoing professional education. However the Associate Professor in Palliative Medicine in NSW, has expressed willingness to provide such support and hopefully there will be a response from agencies within the territory in due course.

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the systematic critical analysis of the quality of medical care including the procedures used for diagnosis and treatment, the use of resources and the resulting outcome and quality of life for the patient.
Nursing Audit:
The method by which nurses compare their actual practice against preagreed guidelines and identify arreas for improving their care. Examples of nursing audit include Monitor, Phaneufs, and Qualpac." pg 9
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Part B: Implementing a strategic plan for cancer services at the regional level

Contents

The National Context

The impact of federal/state relations and the role of non–government organisations is most vividly seen in cancer care and control, where in some parts of Australia the patient can, in the space of a few days, find themselves moving between public and private specialist rooms across the road or around the corner from each other; trail straight to the general practitioner for follow–up medications after hospital discharge for no reason other than a "cost–shift" from state to federal budgets; obtain, in some cases only, information and supportive counselling, which may not be available anywhere near the medical team but be provided by a benevolent society in some other part of the city and, find sorely needed physiotherapy not covered under private insurance and therefore financially inaccessible.

Cancer drugs are expensive and there is increasing use of them for effective treatment. However, clinical devolution of budgets within hospitals, together with the Federal funding of pharmaceuticals has led to 'cost shifting'. It can also happen that within some places, certain drugs are available merely due to the scale of the local pharmaceutical Area Health budget.

Changes in federal/state relations

The federal government's role in health policy has generally been through Section 96 of the Constitution which allows the Commonwealth to make grants to the States on such terms and conditions as it deems appropriate. At the federal level this currently means an expenditure of around $5.5 billion per annum - 30% of portfolio expenditure is provided for 30 specific purpose programs (including $3.5 billion for Medicare base grants). Recently however both Commonwealth and State governments have become increasingly critical of specific purpose programs as a policy tool.

Dr Stephen Duckett, the former Secretary of the Federal Department of Human Services & Health consider not that there is a new climate of cooperation at the intergovernmental level which has moved from endless financial bickering to more strategic issues:

'In part, the new world order is because both the Commonwealth and State Governments have indicated that they want to look at structural change in the health sector from the perspective of patients, regardless of the level of government which actually delivers services or has ultimate responsibility. This has meant that State and Commonwealth public servants can put aside, for the time being at least, their old territorial ways in the interest of designing new approaches to inter–govermental relations.

This is not to say that money and role and responsibilities of the different levels of government won't eventually raise their ugly heads, they will, but it is my view that we have a window of opportunity for us to look at needed improvements in the health system. The new approach is one which focuses on outcomes rather than who does what.[1]

The National Health Policy

The National Health Policy announced in 1994 can be described as historic and its political significance cannot be overstated. A reform agenda has been agreed to by federal and state governments of both political persuasions to develop a shared policy framework for a national health system with the explicit aims of establishing

> *"a framework that focuses on improving health, meeting the health care needs of the community, reducing inequalities in health and making effective use of the resources allocated to health."*[2]

The National Health Policy attempts to refocus away from individual health funding driven by hospital and medical demands towards an outcomes approach to health care. ie. funding services whose intervention has a proven benefit.

The imperatives for this initiative are the acknowledgement of an ageing population, the aspirations and expectations of Australians in regard to their healthcare and the need to define limits and order priorities in the face of unlimited demand.[3] This is a debate requiring political engagement and Health Ministers throughout Australia have shown a commitment to encouraging community discussion as well as participation in policy making.

Two elements were identified as crucial to successfully refocussing the health system to give more attention to better health status and health outcomes, These were:

- a population health focus; and
- a clear pathway through the health system for people, providing continuity of care regardless of who is responsible for funding, delivering or administering services.

It was against this national political backdrop that the ACT negotiated federal funding under the Area Health Management Program of the Medicare Agreement 1992–97 (Schedule E) to pilot a strategic plan for cancer services at the regional level.

This project, housed in the Division of Public Health within the Epidemiology and Population Health Unit has been undertaken by an oncology health service provider (a social worker), in conjunction with a wide consultative membership of medical, nursing and other allied health service providers, together with health educators, epidemiologists and administrators.

National Health Strategy

The Area Health Management Program reflected through the Medicare Agreement the options for change that had been explored in the National Health Strategy. This initiative, undertaken by the Federal Department of Human Services & Health, under the leadership of Ms Jenny Macklin, reviewed health care in Australia. The major vehicle for developing ideas for changes and promoting debate was a series of background, issues and research papers distributed widely throughout the health industry and the community.

Simplicity and stability were highlighted as the virtues of our present funding system – unlike for example the arguably chaotic US health system where 40 million people are uninsured. Extending such an approach to the delivery of health services was the essential goal of the examination undertaken by the Strategy.[4] [5]The principles of universal coverage and equity of access were considered to be the result of the introduction of Medicare in 1984 and strengthened the equity in the delivery of our health care system. [6] Prior to this just under two million Australians were uninsured (ABS 1983).

The Review explored not only how our hospitals are accessed and financed, including a special look at the outpatient and emergency department services, but examined a number of key service areas of expenditure namely medical services, pathology, dental and general practice and sought to provide a range of options [689]

Strategic overviews were also provided in papers which outlined the agenda for change, and explored the question of just how health care delivery could be better integrated and identifying the relationship between accountability and participation [7 8]

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Our health spending as a percentage of GNP is comparable when compared to other countries: (8.1% in Australia , 8.6% in Canada , 11.2% in the U.S. and 6.1% in the U.K 1987). It has increased in the last decade to 8.5% but has remained essentially stable as a proportion of GNP for many years.

In summary, the National Health Strategy expressed concern that the public debate about the pressures on the health system was narrow in scope.[9] A number of key pressures were identified and seen as interrelated:

- the increasing use of health services;
- the difficulties with access to health services of particular groups .e.g Aborigines and the chronically ill;
- the need for an improvement in the accountability of service providers both to consumers and to taxpayers;
- the complexity of the shared fiscal responsibility between federal, state, local governments, the private sector and individuals; and
- a lack of integration of services which means the best mix is not always provided.

These pressures were highlighted in our cancer services project. The problem of continuity of care (because of the varied services provided) was nominated as the most intransigent patient care issue, primarily because of the complexity of service provision.

Public Health & Health Promotion: 1980's & 1990's

Area Health Management is a way of linking program areas which need to come together at the service planning and administrative levels, with population sizes nominated between 200,000– 700,000 people.

The concept embraces an epidemiological focus – a population health focus and by implication, an agreed community understanding of what comprises good health. The debates within the field of Public Health and Health Promotion in the past fifteen years has sharpened enormously, community understanding of what comprises good health as distinct from what constitutes illness.

In Australia, a field of health promotion practice has been built since the 1960's on the activities of such organisations as the National Heart Foundation and the state Cancer Councils, together with organised medical professions and state health departments. From the 1970's the community health movement which has included the women's health movement has also provided both a focus for debate together with innovative models of primary care practice.[10]

The new public health movement as it has been called was accelerated by the World Health Organisation's (WHO) publication of a *Global Strategy for Health for All by the Year 2000* in 1981, which formulated strategies to reduce inequalities in health status between population groups.[11]

With the adoption of the report by the 34th World Health Assembly, Australia as a signatory responded in a variety of ways. The Better Health Commission established in 1985, provided federal leadership in an attempt to begin systematically to investigate and report on the current health status of the Australian population at large. This orientation – a new approach to the issues of a government's role in ensuring its community's good health – led to recommendations being made to the Australian Health Ministers Conference in 1988[12] to develop national health goals and targets with the aim of reducing inequalities in health status among population groups. This effort was significant in providing strategic direction for the new health orientation; although in terms of a technical direction it was limited by the information tools available a decade ago.

The program that was established – the National Better Health Program– injected funds for health promotion at both national and state levels and was instrumental in creating a more substantial infrastructure for health promotion in Australia.[13] A major review of primary health care pointed out that one third of expenditure occurs in this sector.[14] They found however that prevailing practice within the sector does not conform to the basic principles of primary health care as formalised in the declaration of Alma–Ata in 1978 and subsequently adopted by the World Health Organisation and the United Nations. A series of recommendations has therefore been made to move towards the goal of applying the norms of primary health care. Such a strategy, by focusing on health promotion and disease prevention, would have a net "social effort" in its effectiveness and efficiency thus reducing the prevailing inequalities in health..[15]

There has been a conceptual challenge in marrying an epidemiological focus to health service delivery. Generations of medical, nurse and allied health practitioners have not been introduced to such concepts. Politically it became clear by the early 1990's that mainstream health services had not been engaged at all by the concept of the national goals and targets and the ideas still belonged only in the 'fringe' areas of public health and health promotion. Professor Don Nutbeam in the 1993 report *Goals and Targets for Australia's Health in the Year 2000 and Beyond* made the significant comment that:

> *"the health system in Australia continues to be dominated by the process of providing clinical, diagnostic and treatment services, with little reference to improvements in population health status as a consequence of these investments."*[16]

This report however, did succeed in consolidating past efforts and the Australian Ministers Health Advisory Council (AHMAC) responded to various recommendations [17]. The political commitment was reflected in the most effective fiscal process available; the Medicare Agreement of 1993–98 Schedule H, whereby Health Ministers have committed their states to a national health goals and targets framework and a strategy for nationwide coordination, implementation and review. By the early nineties the Australian Institute of Health and Welfare had also begun to publish deficiencies in the data sources of the early goals and targets while acknowledging that measurement of outcomes was still difficult to ascertain. They made a series of recommendations for developing mechanisms for accountability and effective monitoring.[18]

National Health Information Agreement 1992[19]

A forum organised by the Australian Institute of Health & Welfare (AIHW) in 1991 recommended the development of a national health information agreement to address some of the deficiency in Australian health information. Endorsed by AHMAC, federal state and territory ministers together with the Australian Bureau of Statistics and AIHW signed a five year agreement in 1993. It set out to *"ensure the collection, analysis and dissemination of national health information is undertaken appropriately and efficiently."*[20]

The significance of this Agreement lies in the beginning of a fundamental change in our approach to the collection and utilisation of health data.

The National Data Dictionary and Minimum Dataset [21] is already being developed and when completed will provide a framework for the collection and comparison of high quality data for both clinical and community services. Measures to address the lack of national data on specific conditions are also in progress.

Area Health Management

Health care systems have undergone marked changes in emphasis and structure in the past twenty years.[22] The countries of England, Sweden, Norway, New Zealand, Canada, and the United States have introduced area health management models in an attempt to grapple with ways to contain health care expenditure, and Germany has maintained a regional system since post war redevelopment.

A central premise on which the delivery of health care is based is that all health care services, hospital based and community based, can be integrated into one continuum of care.

By using local boards, area health management should enable increased consumer/community participation to define local needs and priorities in the planning, management and delivery of health care services.

It is considered that the advantages of area health are:
- focus on population health
- more integrated health care service delivery with less hospital dominance
- greater capacity for community participation; and
- and efficient rationalisation of services.

Only one study in Australia to date has evaluated the effects of management changes on service delivery in an area health context. Bryson et al[23] examined the impact of various organisational structures on a single program – the Community Health Program. It had been established by the federal government in 1973 and handed over to the states in the early eighties. The methodology for evaluating the area management model was based on the Community Health Accreditation and Standards Program (CHASP) whereby a number of observable indicators measure the degree to which services achieve a given set of standards. Community services were ranked on a series of five functions: control over finance, needs based planning, community input, accessibility, and continuity of care. Community services in three states were selected reflecting three different organisational structures:

- South Australia and Victoria established community health centres **separately incorporated and operated by their own boards of management;**
- Queensland, WA, ACT, & NT, had health centres run directly by the state **health authorities;**
- Tasmania operated its community health services through the **hospital administration:** and
- NSW developed **area health management** to which community health services were accountable.

Results indicated that South Australian services clearly ranked highest in ability to respond to their communities health needs. Managers having control over their budgets, the presence of community members within the management structure, and the support for needs–based planning by the larger health authority structure, gave these services a clear lead in their ability to respond to community needs. However, they were weak in regard to continuity of care, having little direct pressure to deal with the early discharge of patients from institutions, or with the issues of the chronically ill in the community.

Queensland's traditional public service model while providing for stability in the network of community health services, had no community involvement, slow decision making processes and fiscal decisions did not reflect varying regional needs.

The problem of constant organisational change in NSW was highlighted by Ian Lennie[24], Executive Officer, Australian Community Health Association, when in summarising the issues arising from the above study he noted:

> *There appeared to be a great deal of management and planning activity at both area and sub-area level that never really reached the service level. Corporate plans, strategic plans and business plans proliferated without ever really having an impact on services, or, if they did, having little beyond confusing practitioners about what they were supposed to do. One reason for this was that area structures had never really stabilised. The size and number of areas had already changed once during their brief history, and there are currently rumours of more changes.*

Professional Concerns 1992

The Australian Cancer Society together with the Clinical Oncological Society of Australia discussed in the early 1990's the lack of a national organisation responsible for cancer control, cancer care and treatment activities. Many other countries have such national leadership. Out of this concern was born the idea of the Australian Cancer Network (ACN) to provide such a coordinating function.

In November 1992 in proposing the establishment of the Network, the working party of the National Cancer Advisory Committee made the following comments:

> *"Treatment of cancer patients in Australia is provided by general practitioner and specialists through a wide range of public and private health care facilities. However, due to poor coordination of cancer treatment services at hospital and regional levels a number of serious problems have been identified. These are the inappropriate distribution of medical services, variable professional competency, lack of delineation of cancer and associated treatment specialists, unclear budgetary arrangements, inadequate treatment data, lack of universal treatment guidelines and a national shortage of certain cancer specialists i.e. radiation oncologists. National cancer treatment guidelines are one way of improving clinical outcomes and these require urgent development in Australia. Availability and access to new cancer treatments is of great concern to the public, being frequently highlighted in the media. The importance of supportive care for cancer patients during active treatment and in the terminal disease stage is increasingly recognised. Many health care workers and cancer patients feel that some of the urgent mechanisms to make new anti-cancer drugs available in Australia are cumbersome and bureaucratic. If Australian biotechnology is to compete in the world market today, new innovative strategies to support this vital industry are needed. Support for clinical cancer management, including the development of new treatments, is fragmented between various State Health Departments, State Cancer Organisations, National Health and Medical Research Council (NHMRC), Universities and private institutions. Clinical cancer research, especially the evaluation of new cancer treatment, is poorly resourced. New initiatives in the area of controlled trials are needed to:*
>
> ***1. Identify the most effective cancer control strategies, and***
>
> ***2. Gain knowledge of therapeutic outcomes at the local and national level.***
>
> *It is important to progress towards the day when most cancer patients can be offered standard treatment or participation in a clinical trial with appropriate outcomes being monitored. Clinical trials allow ineffective treatments, new and old, to be identified efficiently, resulting in cash savings to the health systems.*

Proposal for the Establishment of an Australian National Cancer Network & thereafter the Development of an Australian National Cancer Control Plan.

(Australian Cancer Society & Clinical Oncological Society of Australia. Inc. Nov 1992).

Parliamentary Concerns: 1993–94

	Parliamentary Debate	**Reports**
1994	Senate Standing Committee on Community Affairs	*Report on Breast Cancer Screening & Treatment in Australia*
1993	House of Representatives Standing Committee on Community Affairs	*Home But Not Alone* Report on the Home and Community Care Program
1995	House of Representatives Standing Committee on Community Affairs	*Report on the Management and Treatment of Breast Cancer*
1995	House of Representative Standing Committee on Legal & Constitutional Affairs	*In Confidence*

Federal Parliamentary Debate:

Parliamentary Inquiries have been one of the barometers of changing political interest in the cancer issue: Both the Senate and the House of Representatives have undertaken inquiries examining the management of the tumor site of breast cancer which is one of the five most common cancers – the others being melanoma, lung, colon and prostate.[25]

The Senate Standing Committee on Community Affairs Inquiry into Breast Cancer Screening and Treatment in Australia 1993/94

Their report[26]comprehensively examined breast cancer screening and treatment with reference to the National Program for the Early Detection of Breast Cancer and made a number of recommendations for its ongoing improvement. These included a national education campaign for both women and GPs with recommendations that the needs of rural women, Aboriginal women, and women of non–English speaking background needed further special attention in regard to their participation rates. They also emphasised that cancer support and counselling services required further resourcing together with quality assurance procedures, to continue to improve standards of care and that monitoring and surveillance be strengthened with the establishment of hospital based cancer registries. (See Appendix A for a more detailed description).

House of Representatives Standing Committee on Community Affairs on the Management and Treatment of Breast Cancer

This report[27] provides a template for the development of effective cancer policy by clearly separating the management and treatment of breast cancer into its two essential strands: clinical care comprising both doctors and paramedics; and patients and their families and carers. It discusses the current situation from both perspectives and makes recommendations for improvements – again from both positions. The Committee was blunt in its observation that:

"While some medical practitioners have stated that Australian women are being provided with the best management and treatment possible for breast cancer, the evidence gathered by this Inquiry would not support such an assertion."[28]

They recommended that multidisciplinary teams need to be established as a matter of urgency and that the concept of medical care be expanded beyond the narrow concept of treatment to include a patient perspective which they described as cancer management.

"It is essential that the concept of 'best practice management' incorporates both the active participation of the woman in the decision–making progress about her treatment, and strong links with general practitioners, counsellors, and community based support services." [29] (See Appendix A for further discussion of the Report).

Government Response to the Committee of Inquiry's Report[30]

In responding, the government acknowledged the Report's patient–centred approach with the emphasis on the woman and her needs rather than just the treatment of a disease which they saw as a focus consistent with the objectives of the COAG reforms for health and community services. However the then minister Dr Lawrence also acknowledged that the recommendations made in the report raised complex issues of Commonwealth, State and Territory relationships.

In the provision of quality, co–ordinated care, the government made specific commitments to addressing the lack of multidisciplinary teams, the need for best practice guidelines, the issues surrounding professional education and liaison and women's needs for information and support in particular counselling. They made commitments as well to undertaking a national data collection audit for breast cancer and further government support into research with increased funding to the NHMRC and the establishment of the Kathleen Cuningham Research Foundation.

House of Representatives Standing Committee on Community Affairs reporting on the Home and Community Care (HACC) program.

It was the same House of Representatives Committee that in the previous year had reported in depth on the Commonwealth Government's Home and Community Care (HACC) program in its report [31]*Home but Not Alone.*

Of particular interest for cancer policy was this committee's exploration of the impact of HACC's "no growth" policy for services designated to people requiring post acute or palliative care since 1985. This committee was unequivocal in its assessment of the impact of this decision:

"Evidence to this Inquiry indicates that the no growth restrictions to post acute and palliative care have contributed to work against continuity of acute health care and community care. [32]

They recommended a model of care be developed that would provide a regional community assessment agency as the point of interface between acute care and post acute care and subsequent HACC long term support where required. (See Appendix A for further details.)

Interest groups

The influence of interest groups on cancer policy development has been well established for many decades. The Australian Cancer Councils have formalised this involvement with federal and state governments over many years and all the major political parties have been influenced by their opinions. Health promotion programs in the interest of cancer control in the areas of smoking cessation and skin protection are two key areas. Patient information through the production of pamphlets and support through the establishment of volunteer programs, have been the other major spheres of activity.

Most of the effort and interest however has been in research where support stretches back to the 1920's. Significant amounts of money are provided annually by the Cancer Councils; in recent years they have been dispensing about $12 million annually in project and program grants.[33]

Individual Foundations have also been established which collectively provide further discretionary funds for medical research. However, there is no national inventory of cancer research funded in Australia and the Charitable Trusts have a surprisingly low profile in regard to their public accessibility.

It is interesting to note that to date this research has almost all focused on the medical challenge of seeking cancer cures. The challenges of living with cancer both in terms of the physical, psychological and social aspects of an individual's quality of life have received very little research attention in Australia. The quality of life research that has been undertaken in conjunction with clinical trials for instance, has been supported by the large pharmacological interests as part of their research and development efforts to improve market share.

However in the last decade or so, two other constituencies have begun to shape cancer policy: namely the palliative care and hospice movement and the women's health movement . Each has been able to influence national government program development in cancer care and control :

> The two screening programs – the Organised Approach to Preventing Cancer of the Cervix (OAPCC) and the National Program for the Early Detection of Breast Cancer (NPEDBC) were both influenced by the concerns expressed by some women that the male medical establishment was not taking sufficient account of the mortality figures in Australia from cancers of the cervix and breast.
>
> Similarly, the slow response of the Australian medical and hospital system to the incorporation of the advances in palliative care into mainstream care was only highlighted when federal funding in the Medicare Agreement 1988 –1993

for the Pilot Palliative Care projects began to unravel the extent of unmet need in the community.[34] Core funding of palliative care services however still does not exist sufficiently to meet demand in most states in Australia.

ACT cancer population profile

The population growth rate in the ACT is due to natural increase and net migration. For the year to June 1991 it was 2.5% per year compared to 1.3% nationally. This trend is expected to continue. Interstate migration is the most`important`contributor to population growth in the ACT. NSW is the major state contributing to the interstate migration which between the period 1988–1992 averaged 1,500. At the 1991 census, 20 per cent of the ACT population had been living in another state five years previously. Net migration is the most volatile of the components of population growth in the ACT, but "net migration levels continues to be strong to Canberra, due fundamentally to the relative strength of the ACT economy and labor market compared to others throughout Australia." With current political change, the levels may well decrease however.

The population projections show an ageing ACT population with older age groups increasing at a faster rate than that of the overall population, in particular, the 45–64 65+ age groups are expected to increase at 6.0% and 4.3% per annum respectively, over the next five years. As most cancers occur in older people one would expect similar increases in service use.

The high levels of recent population growth and ageing of the population shown in these figures has significant implications for service provision in the area of cancer care. People arriving with their often young families, faced with the challenge of a cancer diagnosis, have the added burden of limited family and social support.

The ACT's growth rate being double the national average means there are extra demands on the ambulatory care infrastructure. At the medical level, such projections affect hospital and nursing planning and at the community level, it requires flexible social support services.

Overview of incidence and mortality in the ACT

During the 10 year period 1982–1991 there were 5,708 cancer cases diagnosed in the ACT and in the same period 2,554 ACT residents died of cancer. Table 1 below shows that for both males and females there has been an increase in incidence and mortality. This increase is greater for males.

Table 1. Incidence and mortality of all cancers combined in the ACT, 1983–1992.

Sex	Time period	Number of cases	Crude rate*	ASR (95% CI)*#	Lifetime risk 1 in:
Incidence					
Male	1983–1987	1344	213	287 (273–307)	4
	1988–1992	1717	243	298 (267–296)	4
Female	1983–1987	1385	220	240 (227–253)	4
	1988–1992	1614	228	234 (222–246)	4
Mortality					
Male	1983–1987	628	100	147 (141–167)	6
	1988–1992	784	111	144 (135–156)	7
Female	1983–1987	578	92	106 (96–11)	9
	1988–1992	655	93	95 (90–106)	10

* Rate per 100 000 population. #Age–standardized rate using the World Standard Population with 95% confidence interval.

Most common cancers in the ACT [2]

Of the new cases during 1982–1991 for males, the five most common sites were lung, melanoma, prostate, colon and rectum. Similarly, for females they were breast, melanoma, lung and cervix uteri. Table 2 shows a breakdown of age groups with their most common cancers.

Table 2: Most common cancers in specific age–groups in the ACT, 1988–1992 (per cent of all cancers in that age–group in brackets).

	0–14 years	15–44 years	45–64 years	65+ years
Males	***n = 31***	***n = 254***	***n = 618***	***n = 814***
	leukaemias (37%)	melanoma (31%)	lung (15%)	prostate (21%)
	brain (20%)	lymphomas (9%)	melanoma (13%)	lung (16%)
	lymphomas (10%)	testis (8%)	colon (12%)	colon (10%)
Females	***n = 16***	***n = 338***	***n =639***	***n 621***
	brain (26%)	breast (34%)	breast (34%)	breast (17%)
	leukaemias (16%)	melanoma (28%)	melanoma (11%)	colon (15%)
	lymphomas (11%)	cervix (9%)	colon (8%)	lung (10%)

The most common causes of death during 1983–1992 for females were breast, colon, lung, unknown primary and ovary. For men they were lung, prostate, colo–rectal, unknown primary and stomach.

Future predictions

The numbers of new cases and deaths from cancer have been increasing in the ACT, due in the main to absolute increases in the population. In addition, while the ACT's population is younger on average than the general Australian population, the ACT population is ageing more rapidly than the rest of Australia. *'The numbers of new cases and deaths due to cancer can therefore be expected to continue to rise and this will put increasing strain on medical and support services for people with cancer in the ACT and their families.'*[35] With the ageing population it is expected that the most common sites of cancer for people over 65 will be prostate in men, breast in women, and colon and lung in both sexes. There are no known preventive measures for breast cancer, so the emphasis is on detecting breast cancers at an early age. There are no known preventive strategies for either prostate or colon cancer although screening is available for people with a strong family history of colon cancer.

Site specific cancers

Trachea, bronchus & lung cancer: lung cancer is the most common cancer in males in the ACT and the fourth most common in females for and was the most common cause of death from cancer in the period 1982- 1991. However, the incidence of lung cancer in males is significantly lower in the ACT than in NSW and other states of Australia, although females rates reflect those around Australia.

Breast cancer: was by far the most common cancer in females in the ACT, accounting for 27% of all cancers in females. "About one in every 14 ACT women will develop breast cancer before the age of 74 years, although the incidence rates do not appear to be increasing, unlike other Western experience".[36]
This cancer occurs most commonly in women in middle and old age but there are unfortunately quite high rates in women in their thirties as well: see table 3:

Table 3 Incidence of and mortality from breast cancer in the ACT 1982–1991, Females[37]

Incidence	*1983 – 1987*	*1988 – 1992*
Number of cases	358	478
Percent of all cases	27%	27%
Crude incidence rate*	56.8	67.6
Age–standardized incidence rate*#	62.7	69.2
(95% confidence interval)	(56.1 - 69.4)	(62.8 - 75.6)
Risk of developing this cancer to age 74	1 in 14	1 in 15
c.f. NSW incidence	Higher in ACT	Same
cc.f. North Sydney incidence	Same	Lower in ACT
Mortality		
Number of deaths	123	142
Percentage of all deaths	21%	22%
Crude mortality rate*	19.5	20.1
Age–standardized mortality rate*#	21.7	20.5
(95% confidence interval)	17.8-25.6	17.1 - 24.0
Risk of dying of this cancer to age 74	1 in 42	1 in 47

* Rate per 100 000 population # Age–standardized to the World Standard Population

'Risk factors for breast cancer include family history, reproductive factors and possibly obesity and dietary fat. The number of reproductive cycles a woman has, seems to be related to breast cancer development, with early menarche, late menopause, nulliparity and late age at first full–term pregnancy all increasing the risk. Perhaps because some of these factors are more common in women of high socio–economic class, breast cancer is more common in regions such as North Sydney. It is interesting to note that during 1982–86, the incidence of breast cancer in the ACT was very similar to that of North Sydney and was higher than the NSW rate, but that during 1987–91 the rate was more similar to that in NSW and was lower than the rate in North Sydney. Breast cancer in the ACT may be under–enumerated, as many of these cases may be treated in private hospitals, and may not have been notified.'[38]

Early diagnosis provides the single most effective approach to reducing the mortality rates, which are currently about one third of the incidence rates and do not yet appear to be changing.

Melanoma of skin
Melanoma is the second most common cancer in both males and females in the ACT and the incidence appears to be increasing in both sexes. It was the seventh and tenth most common cause of death from cancer in males and females respectively in 1987–91.
Risk factors for melanoma include pale–coloured skin, the presence of many skin moles, and excessive exposure to the sun. ACT has similar rates of melanoma to NSW and Western Australia, and higher rates than the other states of Australia, except Queensland which has even higher rates.

Prostate: Cancer of the prostate was the third most common site for cancer in men, found predominantly in older men. It was the fourth most common cause of death from cancer in 1982–86 but was ranked second in 1987–91. There were no changes in either the incidence or mortality rates over the period 1082–91. The incidence of prostate cancer has been increasing in NSW and some of this is thought to be due to improvements in diagnostic practices; see Table 4.

Table 4 incidence of and mortality from prostate cancer in the ACT 1983–1992

Prostate cancer		**Males**
Incidence	*1983–87*	*1988– 1992*
Number of cases	114	254
Percentage of cases	10%	12%
Crude incidence rate	18.1	35.9
Age–standardized incidence rate*#	25.2–37.4	43.6–56.3
Risk of developing this cancer to age 74	1 in 33	1 in 19
c.f. NSW incidence	Same	Lower in ACT
c.f. North Sydney incidence	Same	Lower in ACT
Mortality		
Number of death	54	85
Percentage of all deaths	8%	10%
Crude mortality rate*	8.6	12
Age–standardized mortality rate *#	15.1	18.2
(95% confidence interval)	(10.7–19.4	(14.1–22.2)
Risk of dying of this cancer to age 74	1 in 73	1 in 68

*Rate per 100 000 population. # Age–standardized to the World Standard Population

Colo–rectal cancer is the most common cancer in ACT males and second most common cancer in females. While these rates are similar to the US and Canada, they are 10 times those in South–East Asia. These patterns are thought to be due to dietary difference, as it has been suggested that meat and animal fats increase risk of colo–rectal cancer, while a high fibre diet may decrease risk.

Cancer of the uterus: was the fifth most common cancer in the ACT and the twelfth most common cause of death from cancer. Cancer of the uterus, is mostly found in older women and rarely causes death. Cervical cancer occurs more frequently in younger women and if left undetected cancer cause death. Incidence in the ACT remains similar to those in NSW and other Australian states, which is higher than rates in other parts of the western world. Mortality figures have not changed significantly over the past ten years (1982–91).

Oesophageal cancer: While not a common cancer it has clear risk factors associated with tobacco and alcohol consumption.

Laryngeal cancer: Incidence rates are similar to those in other Australian states. The major risk factor for cancer of the larynx is cigarette smoking, so rates for females may rise in the coming decade. Heavy alcohol consumption also increases the risk of developing laryngeal cancer.

Multiple myeloma: was the twentieth most common cancer in both males and females, occurring primarily in people over 50. The females rates in the ACT period 1987–91 were almost twice those in Northern Sydney and NSW. No reason could be advanced for this finding and it is a possibility that this was just a chance finding. Risk factors include radiation exposure and farming as an occupation.

Lymphomas: were the sixth most common cancer in males and the seventh in females in the ACT and about the tenth most common cause of cancer death in both sexes. Incidence and mortality rates have been stable over the period 1982–91. Lymphomas are quite common in people in their 20s and 30s , and while rarely a cause of death can create special needs for psycho–social support in both the treatment and rehabilitation phase. Incidence rates of this group of cancers are rising in many western countries. Some of the additional cases are occurring in people with Acquired Immune Deficiency Syndrome who are at particular risk for this cancer.

Current available cancer services along the Care Continuum

Health promotion and prevention

ACT Cancer Society:
The society was founded in 1969 by Canberra people to serve the community of the Canberra region. It aims to reduce the incidence and impact of cancer in the community by undertaking a wide range of activities.
Education of risk behaviours is undertaken through a number of health prevention programs key amongst them being QUITS. This is an Adult Smoking Cessation & Education program, together with an adolescent program which is regularly presented in schools, clubs and the workplace. Health Promotion is directed to both the QUITS program and Sunsmart which targets lifestyle and behaviour choices in regard to both tobacco use and sun–protection to reduce cancer incidence.

Health Promotion Fund Secretariat:
The Secretariat is located in the health Grants Management Section of ACT Health. Its target group is community –wide.

Objectives are to promote good health and prevent disease in the ACT community and aims in particular to:

- support health promotion and disease prevention programs and campaigns;

- replace tobacco sponsorship of sporting, artistic, cultural and recreational activities; and
- sponsor sporting artistic, cultural or recreational activities that deliver or promote appropriate and effective health promotion messages or campaigns; and support research in the above areas.

The fund administers the program, monitors grant allocations ensuring reports and acquittals are completed. It also has the wider responsibility of advising the Health Promotion Advisory Committee on targets for health promotion and the coverage being achieved by the fund. This is done in consultation with key groups and committees in the ACT and by working with current and potential health sponsors, it aims to ensure that a range of health messages are appropriately tailored to the needs of different groups and individuals.

Health Promotion Services:

There are located within Woden Valley Hospital and provide a service to health professionals, community members and other health agencies as well as direct it to the wider Canberra community.

Services range across the spectrum of information resources – pamphlets, videos, books and manuals, and 24 hour stand displays. Current programs include Quit smoking, Health back and Lifestyle. Promotional displays using visual information themes from local, national and international health promotion sources are conducted throughout the year.

ACT Breast Screening Clinic:

The Clinic offers free screening mammograms to all women over the age of 40 years, and actively encourages the attendance of women aged 50 years and over. For women aged 50 years and over, mammograms are recommended every two years, unless otherwise advised.

The ACT government is providing this service as part of its participation in the National Program for the Early Detection of Breast Cancer. At the clinic two X-rays are taken of each breast and the woman and her general practitioner (if the woman agrees) are notified of normal mammograms within 14 days. Recall is requested in the case of abnormality.

ACT Cervical Cytology Register

The registry provides a complete Pap smear history for individual women including a back-up and reminder system. Pap smears are recommended every two years for women aged between 18 and 70 years who have ever been sexually active. The service is especially committed to ensuring that all significant abnormal Pap smear results are followed up as well as playing a role in quality assurance. It also provides aggregate data to monitor the effectiveness of the National Program for the Organised Approach To Preventing Cancer of the Cervix. This program arose out of concern that despite screening for the prevention of cervical cancer using the Pap smear there were still a number of preventable deaths each year.

Participation in the Registry is voluntary – each woman has the right to stop her Pap smear results being forwarded to the register. Detailed reminder and follow-up protocols have been determined by a management committee to enable the register to alert women or their health practitioners when a repeat Pap smear is overdue. Confidentiality and privacy provisions relating to women, health practitioners and laboratories exist through regulations which restrict access to information of the register.

Health Advancement Unit:
This unit is located within ACT Health and currently provides training for the primary health care workforce.
The two key areas relevant for cancer service provision are the community health centres and community nursing where primary health care services are currently being re–examined to develop multi–disciplinary approaches to service provision. In regard to health education, health literacy, and patient participation in choice of treatment options a primary health care approach where action/learning models are used, can assist in the culture shifts now being demanded.

Family Planning Service: provides a cervical screening service for women that enables records to be transferred Australia wide thus ensuing long–term monitoring is available to women.

General Practitioners: undertake health promotion and health prevention activities as nominated above in their individual patient contact.

<u>Diagnosis & Early Intervention</u>

Medical Services:

General Practitioners:
These provide a medical diagnosis and clinical management service to all members of the Canberra community.
Referral to a specialist for further assessment and treatment is the common practice and for paediatric and gynaecological cancers this may often be to services outside the ACT – generally Sydney.
General practitioners in the ACT operate in reasonably small suburban practices and mostly work in the primary health model especially for those cancers where a poor prognosis is made.

Specialists:
A number of specialist groups are involved in the diagnosis and early intervention of cancer. These include general surgeons, thoracic surgeons, orthopaedic surgeons (only rarely), thoracic physicians, gastroenterologists, haematologists and on occasions medical oncologists for difficult diagnosis. There are a number of pathways (see Appendix B) in pursuit of accurate diagnosis and early intervention .
Referral patterns are informally established between treating doctors and at present no multi–disciplinary group has been established for the purpose of assisting in diagnosis and early intervention treatment options.

Diagnostic Services:
Mammography, CT & MRI scans, cytology, and pathology are provided through the public & private hospitals and private clinics. Costs to the individual are variable depending upon the range of tests performed, where and by whom.

Quality assurance is a matter of substantial variability according to numerous studies undertaken and the ACT has no formal system at present to guarantee that standards are met in all spheres.

Information & Support:

Hospital Social Workers at Woden and Calvary provide information, referral, and individual and family counselling to patients undergoing first line treatment in surgery or for haematological conditions and chemotherapy.

ACT Cancer Society:
The Society provides a wide range of information to cancer patients and their carers. Information is provided through a series of fact sheets which aim to be factual but non–threatening to assist patients and their families to deal with a diagnosis of cancer. The Cancer Information Service also provides telephone support and conducts a library on its premises in the centre of Canberra. The Society's Breast Cancer Support Service is part of a national network recognised for its professionalism and ability to assist women with a recent diagnosis. The service matches women newly–diagnosed with cancer with trained volunteers who have had breast cancer themselves, and ensures that each patient receives the appropriate level of support. Group support is also provided through the establishment of an ongoing cycle of groups.

<u>Treatment and Management</u>

Clinical Oncology Services:

These are provided by specialists supported by a multi–disciplinary team. A comprehensive service is provided at Woden Valley Hospital. Treatment can be undertaken on a first line basis only, or in the case of a lost remission, second and third line treatment options can now be offered in the ACT with the extension of radiotherapy services and the establishment of a Bone Marrow Transplant Unit. Some chemotherapy is also provided at Calvary Public and Private Hospitals, and John James Hospital. The clinical judgement is exercised by the treating doctor, sometimes although not always, in consultation with colleagues.

Surgical treatment is offered for solid tumours in conjunction with chemotherapy on occasions, depending on the current best practice developments. Treating surgeons in the main are either general, thoracic or neurosurgeons.

Radiation Oncology and Medical Oncology can offer early intervention to support optimal surgical approaches but in general they provide curative, adjuvant or palliative treatment depending on the nature of the diagnosis.

A diverse range of professionals provide multi–disciplinary support including oncology nurse specialists, occupational therapists, nutritionists and on occasions, physiotherapists. As well as direct treatment, issues such as emotional well–being and family support are considered. Social workers, as part of the oncology team, offer individual, family and network counselling, liaison with medical staff, help with practical problems, information about transport and accommodation and referral to community services.

Community services are provided for those undergoing active treatment as well as those at the palliative care stage.

Regional Community Centres
There are a range of community–based services providing supportive care to people diagnosed with cancer. The regional community services at Belconnen, Northside, Southside, Woden, Weston and Tuggeranong provide free community transport services under the general direction of a volunteer coordinator in each centre. In addition, community workers for the aged, disabled, and migrants are available to provide family support, counselling, advocacy and friendship visiting. Emergency home help, including shopping, is provided by some of the community services.

Respite Care aims to provide a respite care service to carers, the frail–aged and people with disabilities who live alone or with family or friends. Priority is given to people in long–term caring arrangements or those who would be at risk without access to relief care. Respite carers are personally introduced and carers are available to care for people of a range of different nationalities.

Home Help Service ACT Inc: This service provides home care and housekeeping for the frail aged, people with disabilities and families in crisis. Unfortunately, this does not cater to the needs of many of the cancer patient population.

Mobile Rehabilitation Unit provides assistance to ACT residents who have physical problems with activities of daily living. Home assessment by occupational therapists are organised by the unit and aids ranging from wheel–chairs, to home installation in bathroom and toilet are provided to ensure optimal quality of life.

ACT Library Service: provides a home library service, spoken word cassette library and a mobile library for those unable to attend library centres.

Homebound Service: is provided by the Red Cross Society. Trained volunteers visit frail aged and housebound clients on a one to one basis for up to two hours a week.

CARE (Credit and Debt Counselling Service): provides counselling for moderate to low income people who are experiencing financial problems. they provide one to one counselling and can negotiate with creditors on behalf of clients. Qualified experts in accountancy, taxation ad counselling are available.

Rehabilitation & Extended Care

Medical:
Can be offered by surgeons in some cases, e.g. breast reconstruction.
Allied health professionals also provide services for a range of physical rehabilitation situations. These include the Rehabilitation Unit at Woden Valley

Hospital who assist at times; the rehabilitation team post operatively for neurosurgical cancers; physiotherapists provide assistance to women after breast surgery; speech therapists who offer services to patients with cancers to the head/neck, trachea and larynx, and; stomal services for some patients with colorectal cancers.

Psycho-social support: This area is poorly defined to date.
The ACT Cancer Society and the National Association of Loss and Grief (NALAG) in conjunction with hospital social workers and counsellors is undertaking a community bereavement education program along a preventive public health model to begin to tackle the community burden of the impact of cancer.

Palliative care

Hospital Medical Teams: WVH/ Calvary Hospital / John James Hospital. Radiotherapy, chemotherapy and surgery can be used for palliation as a treatment measure to sustain quality of life. Pain management is frequently reviewed by specialist opinion for certain types of advanced cancer.

Social Workers: Work with medical and nursing teams to provide psycho-social support to patients and their families and ensure appropriate support systems are in place to assist with effective bereavement.

Pastoral Care Team: Work with the hospital team in that setting as well as in the home to ensure spiritual problems are addressed and that the full range of spiritual and religious needs are met.

Palliative Care Nursing Team Assist in daily nursing care and help patients and family regard dying as a normal process. They monitor patient's symptoms and assist alleviate other distressing symptoms with the commitment of enabling patients to maintain control of their daily life at home for as long as possible.

Hospice and Palliative Care Society The society conducts a volunteer program which provides practical and emotional support for terminally ill people and their families, usually at home. The service is provided 24 hours a day, 7 days a week. A live-in carer is sometimes available when families/friends are unable to provide full-time care. Both grief and bereavement counselling is available.

General Practitioners: Provide day to day monitoring of pain control and can support the multi-disciplinary team to assist patients to live as actively as possible until death.

ACT Cancer Society
The society assists community members through its Adult and Child Support Groups to obtain appropriate support in bereavement.

The Strategic Plan 1996 -2000

Five key challenges

The reports of the five working parties and their recommendations (2nd Progress Report to the Commonwealth – *A Discussion of the Consultative Planning Process)* provided the basis of the draft strategic plan under the guidance of a small sub committee. Five key challenges were nominated as the framework in which cancer services needed to be considered and the implementation plan drawing on the Department's principles as enumerated in its recent strategic plan, provides a blueprint for action. This document – **The ACT Strategic Plan for Cancer Services** – shortly to be released publicity is seen as the tool for agencies to begin to focus in a strategic way on their cancer service delivery under the steering of an expert advisory committee.

The Implementation Plan which provides the detail of activities to be undertaken by various agencies is attached as Appendix C.

The Joint Working Party Planning Workshop examined five key challenges that needed to be addressed in this region over the next five years. These Challenges were each discussed by a mixed group of participants, roughly ten people in each (list of participants at the end of this chapter) and their views were then brought back to the main forum. The challenges were;

Challenge One

The involvement of consumers and the participation of the community in cancer care and control

We will:
improve community support services for people living with cancer and ensure that patients and their families are well informed about resources, networks and treatment options available to them.

Measures of success:

- ***The currently unmet needs of people living with cancer will have been identified by research and evaluation.***
- ***Community support services (such as those provided through the Home and Community Care Program) will have become an integral part of cancer care.***
- ***The relationship between hospital and community services along the care continuum for people living with cancer will have been clarified by effective policy development and planning.***

- ***There will be access to crisis medical care for outpatients and improved access to effective pain management at every stage.***

- ***Community information and education programs on the quality of life needs of people living with cancer will be widely available.***

- ***A culture of awareness around loss and change and the needs of the bereaved will have been created through public health leadership.***

- ***The financial needs of people diagnosed with life-threatening disease will have been addressed.***

Workshop Discussion:
The workshop discussion has been further enhanced by consumer discussion within the Oncology Services Consumer Group (OSCG) who had prior to the workshop and since, explored the issues of participation to take account of various ways in which people may wish to be represented and to represent themselves. The following types of participation are seen as current opportunities with the ACT for those diagnosed with cancer and their families and friends to be engaged:

- volunteer: various non-government organisations from the ACT Cancer Society, to the Hospice & Palliative Care Society, to the National Association for Loss and Grief, encourage volunteerism and some members of the OSCG are keen to see a supportive role developed in the acute hospital care area;
- Self help groups currently cover such activities as Canteen (for teenagers), Crystal (for children), Cancer Society's Breast Support Group; Petrea King Support Group, Solace;
- Empowerment & community development is seen as the processes which give local communities control over, as well as input into, the design and operation of health care services.[39] OSCG sees one of its function as providing for cancer patients the opportunity *"to make decisions about their lives and health that are right for them"* as Mertzel said when articulating what he considered were the three aspects of this need:
  - the realisation that one's needs deserve to be met and also one is capable of making decisions to fulfil them;
  - knowing when and how to use this newly discovered voice; and
  - using the voice and wielding power;
- Community Campaigns and Coalitions have been used within the ACT cancer arena for some time as the community campaign for the Hospice, and subsequently the Bone Marrow Unit illustrate;
- Advocacy is a role that both volunteers, self help groups and the formal organisations undertake on behalf of both individual need and issue of community awareness.

Consultation and Representation are two elements of consumer and community participation that the group felt was already acknowledged within ACT Health as the workshop itself and the involvement prior to it clearly demonstrated.

They saw individual patient consultation as a necessary part of effective audit which builds into service provision the key understanding that the patient viewpoint needs to be regarded in all aspects of care, both for the purposes of treatment decision making, and evaluation of patient care and satisfaction.

Representation is a matter that the workshop considered needed further exploration and clarification and the views of the Consumers Health Forum of Australia[40] (CHFA)articulate the issues alluded to in the workshop; namely that committee representation is best served by acknowledging the diversity of interests being served and ensuing consultation within individual organisations is undertaken at a broad level to ensure those interests are balanced. The difficulties at the human level for a Individual representing on consumer interests is acknowledged in the description of the role as change agent requiring personal abilities to take risks, tolerate ambiguity, and be prepared to be "a loner". The CHFA saw the difficulties as very real:

"in contemplating consumer involvement on government committees, you are entering an area fraught with ambiguity, contradiction, and often conflict; you may be starting from a position of weakness; you will often be following somebody else's agenda. You will often feel frustrated, powerless and that you are wasting your time."
For those with a cancer diagnosis where time is very precious therefore, contributing to such activity needs to be acknowledged.

Challenge Two:

To develop resource management systems which reflect changes in the nature of and the need for cancer treatment services.

We will:
develop tools to ensure that within five years cancer care funding reflects epidemiological and technological changes.
Measures of success

- ***Funding of health care services will be determined by output and outcome measures.***
- ***Resource allocation will be clearly linked to the quality of the services and outcomes achieved for patients.***
- ***Effective methods for evaluating cancer care and control measures will have been developed.***
- ***Information systems will have become sufficiently sophisticated to allow the identification as to whether resources are being allocated in an equitable manner.***

- ***Funding of cancer programs and services will be flexible to reflect changes in epidemiology, technology and service mix.***

Workshop Discussion:

This group began its discussion of their Challenges by examining *how resources are allocated now?.* Budgets have been allocated on the basis of *historic funding*. Canberra has the additional problem of being until recently a non–state; part of the Commonwealth. As a consequence it had very little of the financial, social and philanthropic infrastructure of the older cities and regions of Australia that have contributed expertise in the health care systems. It is five years only since Canberra became a separate Territory, three years since the political decision to amalgamate two hospitals into a major city hospital was made, and in the ensuing past two years major reorganisations within administration and service provision have occurred.

The *influence of interest group*s on decision making has been a hallmark of decision making in the budgetary process. Whats wrong with this? the group asked. Funding on the basis of historic need is *rigid and inflexible.* It *may often support services which have become inappropriate/unnecessary.*
It does not respond to changes which impact on cancer services.
Factors that influence cancer services delivery and therefore resource management seen as important in establishing a fiscal framework are:

- *Changes in screening, diagnosis and treatment technologies or processes (may be dramatic)*
- *Changes in need (epidemiology/risk behaviour)*
- *Changes in priority/community expectation.*
- *What tools do we need to do things better?*
- *Need information to evaluate the changing methods of screening, diagnosis and treatment.*
- *Need to be aware of changing cancer trends and impact on service provision –* note casemix to date has been poor at providing such detail in regard to cancer management.
- *Need information about the costs and benefits of interventions.* As well as developing evidence based best practice the need for a fiscal system that accurately portrayed treatment costs in their entirety has still to be developed. Cancer is a complex disease process requiring multiple episodes of treatment and involving various modalities which current resource tools are unable to fiscally measure.
- *Need a criteria for allocating funding (including ways of moving resources from ineffective to effective treatments.) One approach may be to.*
    - *–allocate a base funding to all forms of cancer.*
    - *–allocate funds for examining new treatments/approaches. etc.*

Challenge Three:

To achieve the best health and quality of life outcomes by improving the quality of cancer care in the region.

We will:
work towards an outcomes management approach. This orientation is attempting to integrate various health services research tools into the practice of medicine and health care.
Measures of success

- *An evidence-based cancer control strategy will have been developed.*
- *Clinicians will be able to provide accurate information about the effects of measures to prevent or manage cancer to health consumers and patients.*
- *Patients will report that they were able to make informed decisions.*
- *Comprehensive treatment protocols, based on best practice, will have been developed.*
- *Clinical practice will become increasingly evidence based.*
- *Clinical data obtained from local cancer registries will assist in peer evaluation of clinical practice.*
- *Hospital and community based services will be benchmarked against similar services elsewhere.*
- *Quality of life measures will have been established for cancer prevention, diagnosis and management.*
- *Clinicians accept evidence-based findings and are willing to change their practice accordingly.*

Workshop Discussion:
In the workshop discussion participants made a number of points in regard to the adoption of best practice principles. The group acknowledged it was in fact hard to offer a full definition of principles and guidelines at that point in time:

Best practice includes the use of *treatment protocols, and reported quality of life of patients along the care continuum*. Best practice needed to be adhered to in both institutional and community care settings.

Three kinds of data need to be collected to enable a framework for regional cancer care and control best practice principles to be developed. Data needed to include *clinical analysis, patient care* and *policy analysis.*

Further data needed to be local i.e. acquired from a hospital based cancer registry and, it also required a capacity to be compared with state and national information. The group also believed data should be collected across agencies if continuity of care was to have meaning as a best practice concept. Ownership of data was acknowledged as an issue. Clinicians should own the data and be prepared to modify practice as a result of evidence based research, the workshop group concluded.

Finally this group summed up their discussion by recommending that a Regional Cancer Council needed to be established to provide leadership for best practice to be developed in the manner outlined above and the composition should be a panel of experts including consumers of services, and multidisciplinary service providers from both institutional and community health care areas.

Challenge Four:

To ensure continuity of care in the provision of cancer services.

We will:
provide cancer care services from initial diagnosis through to palliation in order to ensure enhanced continuity of patient care.

Measures of success

- *Clinical audit to assure timeliness of referral for treatment will have become routine.*
- *Clinical pathways will have been developed to ensure continuous case management.*
- *Communication with primary health care professionals will have become streamlined.*
- *Patients will routinely be involved in identifying their service needs.*
- *Patients will be able to keep a copy of their medical records.*
- *Hospital discharge planning will have become family centred to guarantee appropriate home care.*
- *For patients living at home alone, provision of support services will have been guaranteed before hospital discharge.*
- *Community support services will have become enmeshed with primary care provision to guarantee holistic patient care.*
- *Patients will have information about and access to a range of services in the public and private sectors.*

Workshop Discussion:
This group saw there were five main issues that the ACT and surrounding district need address if continuity of care was to have meaning and relevance for patients:

First Issue:
They began their discussion by examining the two concepts of *ambulatory care and outreach services* within the context of such current new ideas as ACT Health's *"Hospital in the Home project"*.

The issues they believed still needing to be addressed include *development of access to services*. Should there be a centralised agency for assessment, referral and case management or should a more piecemeal approach be maintained?

This matter has been addressed in another setting by the House of Representatives inquiry in Home and Community Care (HACC) program which recommends the establishment of a regional referral agency to ensure appropriate services are both provided and needs identified systematically (See Appendix A for some further outline of that proposal).

The second matter for the group in the development of ambulatory care service provision was the question of a *common record for all services. Integrating records with the cancer care centre* has raised a number of thorny matters in regard to patient rights/privacy and their medical records in numerous settings in recent years. The question was of course not settled by this group, merely acknowledged as a matter requiring further discussion.

Second Issue:
The group considered the concerns expressed by some about the *timeliness of referral for treatment* needed to be clarified. The referral pathways which can lead to *delays in appropriate service,* the perception by some of a *poorer ACT service* needed to be addressed. The issues of *education* in both the general community and the *medical community* are seen as ongoing challenges in the next few years.

Again these matters have been raised in both the recent parliamentary inquiries into breast cancer care and treatment as well as the Australian medical literature in regard to the problems of current undergraduate curriculum. Further, medical leadership in the field of cancer care expressed their concerns in an unequivocal fashion when recommending the establishment of the Australian Cancer Network (see Ch 2 of this report for elaboration.)
Third issue:
Discharge Planning – for cancer was seen as *not well covered by the current system.* The group recommended increased *GP involvement and planning of share care* and improved *communication with primary care providers* were matters needing immediate attention.
The issues around this matter involved the question of *timeliness*, an examination of the *type of information* needed for good patient care, a review of the *discharge planning process* and the commitment to ensuing *patient involvement in identifying needs.*

Fourth Issue:
As part of the general discussion the group believed it important to specify the *medico-legal* issues surrounding continuity of care. *The need for documentation* is considered integral to good patient care. However *the depth of information* held for

cancer patients in particular is a real issue. Individual patient files can easily comprise two to three volumes of medical notes in the hospital record system alone *patient privacy* when information can be collected over ten to twenty years becomes a significant challenge if one were to include socio–emotional and psychological aspects of patient care. *Access to the medical record* was considered by the group – *who* has the right of access – patient only and/or nominated family members? All members of the multidisciplinary team? Are there/should there be any restrictions on the access or the extent of recording.
How much, is recorded, by whom and when, is a matter that may need full investigation with an ageing population, increasing cancer incidence and an increasing array of medical treatments to produce quality remissions.
While this group did not address the idea of a patient held record per se the matter has be raised in policy discussions within the Commonwealth. The current Inquiry by the House of Representatives Standing Committee on Legal and Constitutional Affairs in its report *In Confidence* examines some aspects of this issue.

Fifth Issue:
The current *split between hospital and community services* shortly to be formalised with the proposed ACT Health reorganisation was seen as a matter that had ramifications for continuity of care for patients in general but particularly cancer patients whose treatment regime can require outpatient, inpatient and community care almost simultaneously, if a snapshot of a month or two was taken. The issue of case management is still unresolved and becoming more problematic with the changes in health care culture and provision. *Who directs and coordinates*? the group asked.

The vexed issue of resource allocation was seen as stark when examined from the prism of guaranteeing continuity of care. *Shifting resources from areas of need: hospital versus community funding* was the note made by the group and acknowledged to become more of an issue with the division into three statutory bodies. Will there be more *cost shifting* between agencies? How is this to be overcome?

Identification of the appropriate level and complexity of care needed is related to the issue of case management. This issue of medical management in particular was raised by the working party looking at Rehabilitation and Extended Care in their analysis of needs.

Finally it was acknowledged that *interfacing with the private system* was integral to good continuity of care and would need continuing thought if Canberra people were to obtain optimum continuity.

Ian Lennie, Executive Officer, Australian Community Health Association, discussing the organisational impact of area health management make the point that:

"Continuity of care is often a most important issue for service users. In those states under area management with a shared management structure for all health services, community health was more exposed to wider health system issues and problems. This exposure, however, did not in itself result in greater continuity of

care . Indeed, the opposite could be the case where previously integrated primary health care services were being divided between different hospital specialities."[41]

Challenge Five

The provision of community support services that reflect the changing role of the family and society

We will:
work to improve community support services for people living with cancer and to ensure that patients and their families are well informed about resources, networks and treatment options available to them.

Measures of our success:

- ***The currently unmet needs of people living with cancer will have been identified by research and evaluation.***
- ***Community support services (such as those provided through the Home and Community Care Program) will have become an integral part of cancer care.***
- ***The relationship between hospital and community services along the care continuum for people living with cancer will have been clarified by effective policy development and planning.***
- ***There will be access to crisis medical care for outpatients and improved access to effective pain management at every stage.***
- ***Community information and education programs on the quality of life needs of people living with cancer will be widely available.***
- ***A culture of awareness around loss and change and the needs of the bereaved will have been created through public health leadership.***
- ***The financial needs of people diagnosed with life–threatening disease will have been addressed.***

Workshop Discussion:
This group took as given the need for such services to be provided. The Canberra average length of residence is seven years and together with the city's rapid growth has meant it has all the social issues of a new township including the lack of an extended supportive family which provides for most Australians the basis of their psychological and social support. Added to this is the high number of women working in the ACT which while ensuring higher than average income, also demonstrates clearly the vulnerability of such family units when struck by illness.

The need for information and education was the first point made by the seminar group. Community awareness programs in schools in regard to cancer care was seen as important, taking a view that was *broader than prevention.* Such information could present *"the continuum of health".*

In regard to the medical professions' awareness of community support services, it was suggested than both *GP's and specialists* could benefit from the development of electronic information systems e.g. NEWCC which kept them up to date with *availability of services.*

The second issue which the group raised was the *external range of treatment and services not currently available.* Specifically they nominated a number of matters needing to be explored if the framework for an appropriate range of community support services was to be in place for case management. This included :

- assessing and identifying unmet need;
- the variable financial burden to ambulatory patients and inpatients;
- the needs for rehabilitation (the cancer survivor) and convalescent care;
- acknowledgement of the need for counselling to be available from point of diagnosis to bereavement;
- special needs of the aged;
- a change in the criteria for HACC services as many cancer patients are ineligible.;

The group recommended HACC funding could broaden its criteria perhaps by having a fees policy.[42]

The issue of financial support for people living with a cancer diagnosis needed more investigation. They suggested *advocacy support for financial allowances where patients are deprived of earning capacity.*[43]

Measures for success in establishing appropriate community services could include:

- *establishment of a bereavement program;*
- *funding of a palliative care coordinator;*
- *improving access to home help;*
- *continuous ongoing evaluation;*
- *responding to changing needs;*
- *development of suitable data system;*
- *reduction in service waiting time in the community and at the hospital/hospice;*
- *better coordination of services overall;*
- *consumer feedback – surveys etc;*
- *in the case of consumers who have received HACC services prior to admission to hospital, the Regional Community Assessment Agency is to have the authority to direct the hospital to purchase services where appropriate from the provider which had previously provided those services; and*
- *the Regional Community Assessment Agency be responsible for ensuring a smooth transition for the consumer from post acute support to long-term support where this is required in line with the role recommended for these agencies in Chapter 9 of this report (Page 91-92 Home but not alone)*

Purchaser provider model

Theoretical outline

Discussing the reform option for Australia's health system in a recent paper, Andrew Street[44] explained the history of the twin themes influencing review of health service delivery around the Western world.

It was Alain Enthoven who first formulated his ideas about **managed competition** in the 1970's in the context of the United State's health system. It was these ideas that have formed the basis of the Clinton administration's reform package. In 1985, Enthoven produced a paper addressing the future of the National Health Service in the United Kingdom which became the blueprint for the reforms introduced in 1989 – the **purchaser–provider split**. He also provided direction to the Dutch who began a re–evaluation of their health system in 1987.

Distinction between purchaser–provider and managed competition.

The purchaser/provider separation is designed to introduce competitive elements into what is essentially a publicly financed health system. First introduced into New Zealand and subsequently the UK, it has been followed by Western Australia and South Australia and is to be introduced into the ACT shortly. Finland and Sweden are undertaking pilot projects.[45]

Managed competition has been introduced into the US and the Netherlands where the roles of purchasing (those responsible for demand) are already separate from that of provision (those supplying services.)

Purchaser/provider aims to form a health care market, separating demand from supply; whereas managed competition aims at reforming the existing market by focusing on purchaser (insurer) behaviour. Andrew Street puts it thus: 'the main thrust of purchaser/provider separation is towards promoting competition among providers, whereas under managed competition it is competition among purchasers which is of prime concern'.

The purchaser/provider separation

The theoretical aim is to develop a hands–off approach to the day–to–day running of the health system. Regulatory functions are established, funds allocated to budgets, and governments focus on the financial and performance audit of purchasers. The audit of providers is left to the purchasers with whom they have a contract. The critical element of a purchaser/provider element is the process of competitive tendering, or contracting designed to encourage competition among providers.

Value of a purchaser/provider separation:
The (theoretical) value of a purchaser/provider separation according to Street is"enhanced efficiency in terms of both the mix of services delivered and the cost of producing them, and to facilitate a greater responsiveness to consumers."

Allocative efficiency: shifting resources
In practice it is still difficult to determine whether such efficiencies have been achieved in either New Zealand or the UK. While methodologies to ascertain optimal resource allocation are in their infancy as are the tools for evaluating the marginal costs and benefits of different health intervention, there is a strengthening of the theoretical position. The most striking example in the UK which Street cites has been the closures of London hospitals where consumers had little choice but to travel and the allocation of funds to hospitals closer to the population drift. Note however the same result was achieved in NSW through Area Health Management weighted per capita population funding.

Technical efficiency: increasing productivity
The contracting process is supposed to encourage providers to reduce continually the cost of providing services so they do not lose business. Contracting frequently fails for the following reasons:

- Natural monopolies (as they exist for instance in the ACT) where only one main service is provided. Even where competition exists, it can be short-lived because the other local competitor forced out of business destroys the competitive advantage;

- Quality can be a causality of competitive tendering related to the asymmetry in information between provider and purchaser. Quantitative details such as price and volume are much easier to measure than qualitative details;

- Information inadequacies in purchasers predicting accurately their population's requirements for each service and to allocate their budgets accordingly. Need high quality epidemiological research and development infrastructure as is the problem in cancer service provision;

- The contracting process itself is costly. It require considerable resources to both bid for contracts and to evaluate tenders. Critical appraisal skills of health policy makers in the purchasing area is essential. A recent UK study[46] found the way in which the results of a randomised controlled trial and a systematic review are presented, influences health policy decisions. The willingness to fund either a mammography program or cardiac rehabilitation program was significantly influenced by the way in which data were presented. The mean estimate obtained with the relative risk reduction for both scenarios was distinctly higher than the mean obtained with the other three methods. Furthermore, such differences are most extreme when the background susceptibility – in this example, death from breast cancer – is lowest[47] ; and
- Competitive tendering also introduces an adversarial element into the health system.

The interesting outcome to date according to Street is not the theoretical one of increased competition improving efficiency, because in fact it has not; but the assertion that technical efficiency has improved in the UK because contracts make 'more explicit' the way in which resources have been used.

Consumer representation:
The purchaser/provider structure does not in itself guarantee consumer involvement. The UK government is encouraging community views through some consultative mechanisms and there is a view that decentralisation in itself will ensure more responsiveness although no evidence has yet been advanced for this belief.

The fundamental weakness of the purchaser/provider model in Australia is the current opportunity to cost shift. State governments can control their budgets by cutting services and encouraging the local population to seek private provision which is underpinned by the Federal government through Medicare.

Current main options for health system funding in Australia: Eager's Model
K Eager provides the following overview of the three types of options currently available to fund the health system:

Cost–based funding

Health care providers report their expenditure and are reimbursed what is judged to be reasonable. There are few incentives to contain costs – it is seen as simple but unfair; for there are:

- few incentives to improve continuity of care
- few incentives to improve equity of provision of care
- few cost containment incentives
- few incentives to produce good clinical data
- few incentives to measure unmet needs
- few incentives to understand costs.

Needs–based funding

Are established in NSW, Queensland, and Tasmanian resource allocation formulas. Funds are split between service providers in proportion to their service populations weighted for need. Funding is determined by the need of the population to be served, based on principles of population equity and access to services. It is therefore seen as ethical and fair. However, technically it is difficult to identify service population and to measure need.

Incentives created by this funding were summarised as follows:

- good incentives to improve continuity of care, because the funder is purchasing population coverage rather than specified services;
- good incentives to improve equity of provision because there are some cost containment incentives as funding is based on a global allocation;

- some incentives to produce good clinical data at least to the extent that clinical data demonstrates population need;
- strong incentives to measure unmet needs because funding allocations are weighted for population need ; and
- some incentive to understand costs.

Output–based funding

Health care providers are funded based on what they produce rather than the cost of the production. To date, health outputs are patient care episodes, usually classified by casemix. A key feature of this model is that it is technically difficult and encourages productive efficiency. This model may lead to risks to continuity of care if not designed with care. Incentives created by output–based funding are:

- few incentives to improve equity of provision of care;
- few incentives to improve continuity of care because funding is provided for each discrete patient care event rather than for a full episode of illness;
- good cost containment because funding is determined independent of the actual cost of production;
- strong incentives to produce good clinical data because each output is adjusted to take into account the casemix;
- few incentives to measure unmet needs because funding is provided based on what is actually provided rather than on what the population may need; and
- strong incentives to understand costs.

Health outcomes

Eager's view was that a blend of needs and output based funding models would provide the best incentives for a focus on outcomes while maintaining a concern with productive efficiency.

The National Health Policy, endorsed by all Australian health ministers in 1994 has committed the health system to an outcome based approach to clinical care. Such a commitment it is acknowledged, requires considered incremental change. The policy and funding framework to achieve an outcomes focus is considerable.

- Firstly, an organisational culture has to be established which is oriented to health outcomes and also health gain.

- Secondly, tools have to be produced for measuring health status and health gain which may then produce an outcomes culture as a by–product.

- Thirdly, funding can be provided for those health interventions which are believed to result in the best health gain.

- Fourthly, funding can be linked to actual health gain achieved.

Why should we focus on health outcomes?

- To improve the health status of the population;

- Provide information for health service delivery;

- Explicit health care priorities can be developed which may assist resource allocation dilemmas;

- Health outcomes can create a common language for funders, providers and consumers if the right process is developed.

Eager warns that "*based on past experience, we may not have the incentives, the stamina, and the patience to maintain the necessary level of commitment.*"

Outline of a purchaser/provider split for cancer services using the South Australian model [48]

The purchaser / provider split separates conceptually, functions already being undertaken within an organisation. The aim of the redesign is to offer greater accountability, transparency and value for money. The outcome of this approach in theory ought to ensure that if rationing is occurring by default, (for example in cancer care through invisible queues) then examining health service priorities is a fundamental necessity if issues of equity and access are to have any significance.

The key element of a purchaser/provider model is the division of health service provision into four distinct roles:

Funder: identifies source of funds, allocates those funds to purchasers of services and ensures that those services address the appropriate health outcomes and improves the health status of the whole population.

Purchaser: acts as the agent of the funder to secure the required services in the right volume delivered at the right quality and at the right price. With the role separated, the purchaser is free to write contracts with whomever they please because they are no longer accountable for managing the funding side of the system. Critical however to their success is appropriate consultation with their population to assist in determining the right mix and location of services. They need to be concerned not only about price and volume, but also quality standards being purchased.

Provider: This role is to deliver the services they have been contracted to provide at the appropriate price, volume and quality. This is where most of the health care provision takes place. Providers will no longer be deciding what to provide but rather will be providing those services that have been purchased by a purchasing agent. Inefficient service providers should no longer be propped up and providers will need to develop services and packages of care that attract patients and their doctors and encourage funders and purchasers to buy those services.

Owner: The primary role is to provide a return on assets. This distinction enables greater transparency. No longer will building maintenance be able to be run down when money is tight in order to maintain the level of services. Providers –

hospitals for example – could lease their land and buildings from another party who ideally is the minister of some government instrumentality to ensure assets are not stripped and hospitals turned into development sites.

Funder

South Australian Model

Role:

consolidate funds from a variety of sources;
provides policy and planning framework within which purchasers and providers will operate;
develops a set of goals and targets for the total population;
allocate funds to purchaser and owners on an equitable basis.

Function:

. Attracting, consolidating and allocating funds,
. strategic planning, developing policies and
. monitoring to improve outcomes in the status of the whole population.

Activity:

. develop overall policy framework for owners, purchasers and providers to operate within;

. undertake system-wide strategic planning including policy implementation;

. involve community in broad policy development;

. seek funds, consolidate funds from Commonwealth, state and private sources;

. allocate funds and develop funding contracts with purchaser and owner.

. monitor contract performance;

. ensure accountability for making progress towards specific outcomes responsible to Parliament.

It is anticipated that these functions will be performed by the Epidemiology Section and Policy & Planning Branch.

Federal Funds:
Currently federal funds come tagged with specific program requirements which will require some adjustments for the purchaser/provider model. Programs involved include:

Palliative Care Program, Program for the Early Detection of Breast Cancer, Organised Approach to Preventing Cancer of the Cervix, all General Practitioners, a percentage of the private practice of treating Specialists, some key Pharmaceuticals are all funded under federal jurisdiction.

State Funds:
Consolidating funds for cancer services would be difficult to identify with the current casemix system which is oriented to acute care only and this accounts for only some of the medical provision of cancer care.

ACT policies will need to be developed in conjunction with professional groups as has been undertaken in the Strategic Plan for Cancer Services and the above federal programs. The health, goals and targets program has been established (although with only minimal infrastructure support in the ACT) in conjunction with the Commonwealth. Some data is already available through the cancer registry providing details on the incidences and mortality of cancer within the ACT. Determining the priorities and the desired health outcomes for cancer will be a long–term project that needs to be undertaken in conjunction with such national bodies as the NHMRC and professional associations, and will require input from people with clinical backgrounds, epidemiological knowledge and demonstrated negotiating skills as ongoing evaluation in the UK is demonstrating.

Purchaser

South Australian Model

Role:

- *establish the needs of the population for which it is purchasing services;*
- *determine priorities for the provision of services;*
- *determine the units of service it is prepared to purchase, and the price it is prepared to pay;*
- *promote innovation/service development amongst current providers in meeting community needs and encourage alternative providers to enter the field;*
- *develop contracts with providers based on population needs, priorities, price and quality;*
- *set performance indicators, best practice benchmarks, standards and guidelines for providers;*
- *monitor the performance of providers against the purchasing contract.*

Function:

Planning, purchasing and evaluating, through a contract process, the delivery of services to meet the needs of a specific community.

Activities:

Planning

- *undertake needs based planning and develop planning models within the policy and planning framework set by funder;*
- *identify gaps in needs and set priorities.*

Consultation

- *undertake community consultation in needs assessment and with providers in choices about services through full and adequate participation.*

Purchasing

- *negotiate and set contracts with provider organisation, ensuring access to services;*
- *responsible for ensuring through contract provision and continuity(by specifying the quantity, quality, location and prices) of services;*
- *responsible for purchasing in ways that ensure priorities for improvement set by funder are achieved. e.g.*
  - *community and consumer choice*
  - *equitable access*
  - *optimum efficiency and effectiveness*
  - *appropriateness of interventions and care*
  - *customer focussed and driven services*
  - *integration and continuity between primary, secondary, tertiary and continuing care and*
  - *the right balance of care a nd resources between these levels.*

Monitoring & Evaluation

- *Monitor and evaluate the cost-effectiveness and appropriateness of services purchased.*

Accountable

- *accountable for purchasing appropriate services which exemplify value for money;*
- *accountable to funder for financial resource allocation;*
- *accountable to funder for operating within policy and planning framework.*

At present very little infrastructure is available for cancer care and control in the ACT. The data needs identified elsewhere in this paper clearly indicate the current weakness in any attempt to provide effective cancer service planning.

Even a relatively simple task such as projections based on current figures becomes complex because of the changing baselines for recorded incidence; for example, the mammography screening program will predictably in the short run create an increase in the incidence (and therefore treatment of) breast cancer. However, the

program is designed to reduce the mortality rates and so measured in terms of quality of years gained (QALY). Similarly, SA has recorded a substantial leap in the recorded incidence of prostate cancer in the past year – a 30% increase. Projections based on figures for 1993 as compared to 1995 may well show vast and quite likely incorrect forecasting of service need and treatment outcomes.
The social health needs of people living with cancer, and counselling and other support activities have not been systematically evaluated. Workforce planning in cancer service provision requires data that is not yet available. Even basic details such as the type of patients seen for various tumor conditions is not collated in any systematic fashion.

Provider

South Australian Model

Role:

- *ensure the provision of services in line with the contract of purchasers*
- *seek improvements in the efficiency, effectiveness and quality of services provided.*

Function:

Offering and delivering high quality services to customers, as competitively as possible, in relation to efficiency, cost–effectiveness and appropriateness, in the interests of its customers.

Activities:

Planning
- *develop Business Plan identifying services to be delivered within purchaser's plan and funder's policy and planning framework;*
- *Identify opportunities for services and funding from other than public purchasers;*
- *develop competitive services.*

Providing Services
- *provide services as specific by purchasers in accordance with Business Plan;*

Community Consultation
- *consult with customers about quality and appropriateness of services provided;*

Management
- *manage staff, outpouring activities where appropriate and manage assets*

Monitoring & Evaluation
- *monitor and evaluate service provision to improve efficiency effectiveness and appropriateness;*

Accountable
- *accountable to purchaser for achieving most cost–effective mix;*
- *accountable to funder to operate within human resource and financial policies set by funder within overall policy and planning framework;*
- *accountable to owner for efficient operation and maintenance of assets.*

The provider's role is to ensure services are provided in accordance with negotiated contracts. For patients to be assured that quality care is maintained, the key element in this process is that the negotiation process for clinical care is not a matter of simple or easy judgement as the vast range of literature demonstrates.

A strategic approach to improvement in the efficiency, effectiveness and quality of services has been developed by service providers in the Strategic Plan for 1996–2000. However, for implementation to be effective, infrastructure support needs to be provided. The burden of cancer incidence rises inexorably month by month and clinical staff are by the mere absorption of this load, clearly improving their efficiency and productivity.

Business Plans have already begun to be established and it would be envisaged that this will continue and improve with experience.

Owner

South Australian Model

Role:

- *ensure that, in accordance with the priorities of the funder, assets are acquired or made available to enable services to be offered by providers;*
- *ensure that assets are maintained and made available in a way that optimises service efficiency;*
- *arrange for funding of assets.*

Function:

Ensuring that the ownership interests and funding for acquisition of assets provided by the government to public sector providers are optimised.

Activities:

- *develop policies relating to ownership function;*
- *plan asset management and long term capital infrastructure;*
- *monitor performance of provider organisation including return on investment and asset management;*
- *Accountable for optimising government ownership interest;*
- *responsible to Parliament.*

The most significant ACT asset for cancer care is currently the hospice. Calculating a projected asset base for the predicted increase in the cancer population will be an issue that requires long-term planning e.g. the numbers of beds required, size and scale of plant and machinery- diagnostic, radiotherapy (size of building) correlates with the nature and extent of treatment modalities undertaken on ambulatory patients. Data is not yet available for this type of analysis. It maybe within five years when the hospital-based registry has developed a profile of cancer activity.

Relationships are also not clear-cut. A simple example – patients who are well informed in regard to their condition and have adequate social support in the community including appropriate medical and nursing care are less likely to seek emergency admission through casualty. If there is a cut in service provision however, impacting on quality of care, then patients and families become anxious and/or stressed and unable to cope and are therefore more likely to seek hospitalisation thus shifting the balance of demand/care to the acute care system. Studies examining these types of issues for cancer care need to be undertaken in the Australian context.

Research, data and information needs and clinical audit

The following research, data and information requirements together with some possible clinical audits have been extrapolated from the identification of cancer health care needs along the care continuum. They are examined within the proposed purchaser/provider framework for the ACT.

Funder:

Develops, monitors and reviews goals and targets for the cancer population and develops policies.

The infrastructure for this task is still only minimally developed at present, both at the regional level and nationally.

The national goals, targets and strategies [49] endorsed by the Australian Health Ministers Advisory Council (AHMAC) as well as identifying where better control of cancer could improve mortality, have identified opportunities for health gain that can be made in the areas of treatment, support services and palliative care. They have as well identified that education and training for health professionals together with research and data requirements are essential infrastructure to provide these outcomes.

> *Cancer research and data management systems will provide the necessary foundation for achieving these health gains.*
>
> *All the goals and strategies identified in this report fit within the framework of improving the quality and quantity of life for all Australians, reducing inequalities in health outcomes, and involving Australians, both individually and collectively, in decisions about their health......*
>
> *Many of the recommendations in the report, such as new research directions or data monitoring systems, are first steps towards an improvement in cancer outcomes. Other recommendations will have a direct impact on health, either in the short term or long term....*
>
> *The implementation of some recommendations will incur additional costs in the short term, but they have the potential to decrease overall costs substantially in the long term.*[50]

National Cancer Goals [51]

Primary goal

- *Reduce the incidence of, mortality from, and impact of cancer on the Australian population.*

Other Goals

- *Reduce the incidence of cancer in Australia, especially lung cancer, skin cancer and cervical cancer.*
- *Increase the disability-adjusted survival rates from cancer in Australia, especially from skin cancer, cervical cancer, breast cancer, colorectal cancer and prostate cancer.*
- *Provide optimal cancer treatment to all patients requiring care.*
- *Reduce health inequalities related to cancer treatment, prevention and control in Australia.*
- *Ensure high levels of screening for early detection of cancers where there is a scientifically demonstrated benefit at acceptable cost.*
- *Reduce the prevalence of smoking.*
- *Provide quality information and support services to all cancer patients and their families.*
- *Maximise the quality of life and dignity of death of people with incurable cancer and ensure adequate support for their families.*
- *Improve the collection and dissemination of cancer data across all states and territories, including data on screening outcomes and risk factors.*

The National Health Information Management Group[52], established to implement the above strategies in reviewing the work of its Better Health Outcome Overseeing Committee (BHOOC), summarised the principles of the new approach to National Cancer Health Goals and Targets which is clarifying the conceptual thinking taking place around the country (see appendix E for outline).

The data requirements [53] that have currently been outlined are included in Appendix E as a guide to the direction the Australian Institute of Health is encouraging states and territories to take. Work is continuing on the indicators to determine

- what information is now available nationally and at territory level;
- whether an existing methodology maybe available for information currently not available; and
- where methodologies still need to be developed.

Where methodologies are still required to be developed the need for research questions that properly reflect a patient/consumer orientation is urgently required as the NHMRC's consumer literature search graphically indicates and the discussion of the literature in this document supports.

Develop cancer policies

No national cancer policy exists in Australia nor anything as comprehensive as the range of US or UK documents. As the discussion in this report indicates there is a need for ongoing research and policy development along the whole of the care continuum.

The identification of health needs as already discussed highlights areas of immediate research that is required.

Some research needs across the cancer care continuum:

- **Conduct regular surveys to establish the incidence of non-skin cancer in the ACT**
- **Regular surveys of cancer attitudes, beliefs and sources of information**
- **Survey of GP cancer screening practices**
- **Undertake surveys to examine referral patterns, treatment and service use.**
- **Develop applied research models into effective communication for cancer care across the care continuum**
- **Research the psychosocial needs of patients diagnosed with cancer and their families and carers in the ACT**
- **Undertake surveys of quality of life and other outcomes**
- **Develop agreed clinical indicators of cancer health outcomes**
- **Undertake literature search of the rehabilitation needs of cancer 'survivors'**
- **Research into Bereavement Needs and Services**

The following details are the information and data requirements that underpin any evaluation of current services. They are of course a prerequisite for the proposed contracts within the purchaser/provider model if such contracts are to have purpose beyond an administrative burden on the system.

Information & data requirements across the Care Continuum

Health Promotion/Prevention

- Review the literature to identify best practice in anti-cancer health promotion
- Develop baseline data on the community's levels of personal health knowledge including literacy levels
- Characterise groups within the population at high risk for specific cancers
- Monitor risk factors and risk behaviours for cancer

Diagnosis & Early Intervention

- Maintain population based registry to examine incidence and mortality trends and projections of cancer
- Establish a process to determine interval breast cancer rates
- Evaluate cost effectiveness of breast and cervical cancer screening
- Monitor the incidence of cancer by tumour site
- Conduct regular surveys to establish the incidence of non-melanocytic skin cancer in the ACT

Treatment & Management

- Continue to monitor the survival of cancer patients by tumor site through publication of population registry data
- Quantify hospital cancer burden by tumor site*
- Identify high risk groups of poor service utilisation*
    - Examine association between service utilisation and health outcomes*
    - Assess service utilisation patterns in the ambulatory setting*
- Develop data collection for community support services of cancer patients

Rehabilitation & Extended Care

- Identification of cancer prevalence by tumor sites.*
- Identification of cancer prevalence by key demographic variables.*

Palliative Care

- Obtain quality of life measures for patients and carers.*
- Development of outcome measures such as choice of provision and location of services.

* Requires the establishment of the hospital-based cancer registry together with associated data collections.

Purchaser:

Receives funding to meet the identified needs and priorities of the cancer population.

Determining the needs of the cancer population requires an acknowledgement of both the medical and psychosocial aspects of cancer treatment and management along the care continuum. The task is continuous and complex as the earlier part of this paper documents and if the principles of equity and access are to be maintained then there are some key information and data requirements that are urgently needed.

The experience in the UK has confirmed that "*the key to moving towards a convergence of interest amongst purchasers and providers is collaboration.*"[54]
At present it is not possible to determine how much treatment is undertaken here in Canberra and how much is provided elsewhere. Similarly, the figures for NSW use of ACT amenities is only of a ball-park nature as the profile cannot be extrapolated for detailed treatment.

The following outline indicates the immediate information and data requirements for an effective purchasing function for cancer services:

Information & Data Requirements in the ACT

Health Promotion/Prevention

- **Evaluate health promotion model of practice for cancer prevention and monitor population activity**
- **Monitor trends and determine estimates of those within the population at high risk for specific cancers**

Diagnosis & Early Intervention

- **Monitor and estimate interval breast cancer rates**
- **Monitor and estimate the incidence of cancer by tumour site**

Treatment & Management

- **Monitor the survival of cancer patients by tumor site***
- **Quantify hospital cancer burden by tumor site***
- **Monitor trends and determine estimates of high risk groups of poor service utilisation***
- **Examine cost-effectiveness of services***
- **Assess service mix in the ambulatory setting***
- **Quantify the level of community support services for cancer patients**

Rehabilitation & Extended Care

- **Identification of cancer prevalence by tumor sites***
- **Identification of cancer prevalence by key demographic variables***
- **Development of casemix classifications***

Palliative Care

- **Obtain quality of life measures for patients and carers**
- **Development of outcome measures such as choice of provision and location of services**
- **Development of casemix classifications**

* Requires the establishment of a hospital-based cancer registry and associated data collections.

Provider:

Offers and delivers best practice to cancer patient populations efficiently and effectively in accordance with purchaser requirements.

Research to identify best practice

Research is the systematic and creative process of enquiry seeking new knowledge. Evaluation needs to be undertaken by the appropriate professionals and their organisations. In cancer management this will continue to be a difficult challenge because of the multidisciplinary boundaries.

Data needs for resource management which refers to clinical workload, clinical practice and clinical outcomes is the prerequisite to determining efficient service provision.

Clinical care refers both to patient's medical and their psycho–social care.
In the ACT and elsewhere in Australia there is an urgent need to know of the burgeoning cancer population what is their stage of disease, what kind of treatment are they receiving , from whom and where. It is these details that will assist service providers in their referral patterns.

Randomised controlled trials will continue to provide the basis for evaluating the most accurate and effective treatments of clinical practice. It is this approach to medicine that ensures scarce resources are not wasted and provides the research basis for new treatments to be introduced on a wider scale into routine practice. That Woden Valley Hospital Oncology Services is already a participant in national and international trials is a reflection of the high quality of clinical practice already being undertaken in the region, which is the population's insurance for quality care. The physicians' efforts to maintain these standards need to be acknowledged and encouraged with infrastructure support.

The critical issue for any healthcare reform is that the Providers must identify with the Funder the best mix of services so that Purchasers can determine what to buy. The Cancer Expert Advisory Group would be a pivotal group in assisting in the development of such a collaborative approach.

Assessing treatment patterns

The Hospital–based cancer registry will provide clinicians with information on treatment patterns. Assessing survival rates and other quality of life outcomes, enables physicians to determine whether they are meeting the expectation, based on the scientific literature and other information sources, including purchaser guidelines.

Clinical Audit

Audit has only recently become part of the language of medicine. CD Shaw[55] defines it thus:

the objective review of patterns of care sensitive to the expectations of patients and other clinical disciplines and based on scientific evidence of good clinical practice and highlights three challenges in its development which he nominates as coming from other specialities, managers and purchasers and particularly from patients:

> *"The first challenge of developing medical audit into multidisciplinary clinical audit is less of an issue in palliative care than it is in more medically dominated specialities, although it still requires a reconciliation of differing views on care planning and the scientific basis of clinical practice.*
>
> *Second, there is an increasing tendency for manager, many of whom see no tangible signs of benefits emerging from clinical audit to want to direct the audit agenda and to see the detailed results; this underlines a need for prior agreement on confidentiality of audit data and explicit specifications of the purpose, nature, and products of clinical audit in return for the resources invested.*
>
> *Third, there is a growing concern among the population as a whole to know not only that there is a general mechanism for ensuring clinical quality but also to know specific results and performance measures for individual units; the most constructive professional response to this pressure may well be to empower patients by providing them with clear indications of the level of service which they could reasonably expect and by which they may judge for themselves the quality of clinical practice.*
>
> *However, it must be recognised that there will remain areas of technical competence in which both patients and managers will have to rely upon the professional to regulate themselves - and to demonstrate that they are doing so. The clinical professions still have the opportunity to take this initiative and to work constructively with patients and managers in improving quality. This requires co-operation locally and networking and leadership nationally."*

Clinical Audits

- **Develop benchmark for giving consent for cancer treatment using NHMRC guidelines;**
- **Develop program to evaluate communication effectiveness within multidisciplinary teams;**
- **Develop a quality assurance cancer care and control program;**
- **Audit best practice protocols by tumor site at regular intervals;**
- **Develop clinical audits for total cancer management within hospital and ambulatory setting.**

Appendix A:

Membership of Reference Group and Working Parties

ACT Reference Group for the Strategic Planning of Cancer Services

Ms Anne Wentworth ACT Community Representative.

Mr Peter Field, Member Oncology Services Consumer Group.

Mr Russell McGowen, Member Oncology Services Consumer Group

Mr Geoff Caldwell, Member Oncology Services Consumer Group

Ms Jenny Brogan, Director, Womens Health Unit.

Dr Brian Richards, Executive Director, ACT Division of General Practice.

Dr Paul Craft, Director, Medical Oncology. WVH.

Mr David Rhodes Director, Health Professional, WVH.

Ms Trish Towning, Executive Director, ACT Respite Care.

Mr Geoff Bowcock, Executive Director, ACT Cancer Society.

Ms Shirley Sutton, Director of Palliative Care, ACT Community Nursing Service.

Mr Rod Lambert, Executive Director, ClinicaL Services, Calvary Hospital.

Mr Paul Rollings, Chief Executive Officer, John James Memorial Hospital.

Mr Damien Farrell, Executive Director, Information Services Branch.

Mr Bill Stone, Director, Services Policy & Planning.

Dr Bruce Shadbolt, Director, Epidemiology & Population Health.

Ms Kate Burns, Project Officer, Epidemiology & Population Health

Health Literacy Working Party

Chair: Mr Geoff Bowcock, Director, ACT Cancer Society.

MsCharlane Weibanger, Womens Health Unit

Ms Jenny Satrapa, Member of Oncology Services Consumer Group

Sr Pauline Bairnsfather, Medical Oncology Outpatients Clinic

Ms Denise Montague, Policy & Planning, ACT Health

Ms Di Roberson, Director, Health Promotion, WVH.

Ms Penny Birtles, Social Worker, Oncology Services, WVH.

Ms Kate Burns, Project Officer, Cancer Strategic Plan

Diagnosis & Early Intervention Working party

Chair: Ms Jenny Brogan, Director, Womens Health Unit

Ms Caroline McNally Div of General Practice.

Dr Jeff Rodgers Div of General Practice

Dr Ian Prosser, Clinical Director, Haemotology. WVH

Ms Cathy Smith, Member of Oncology Services Consumer Group

Ms Veronica Hourigan, Member of Oncology Services Consumer Group

Mr Geoff Caldwell, Member of Oncology Services Consumer Group

Ms Nancy Wilkinson, Senior Social Worker, Oncology Services, WVH.

Sr Inga Neilson, Oncology Nurse Specialist, Community Nursing.

Ms Kate Burns, Project Officer, Cancer Strategic Plan

Treatment Working Party:

Chair: Dr Paul Craft, Director, Medical Oncology. WVH

Mr Damian Farrell, Executive Director Information Systems, ACT Health.

Dr George Jacobs, Director, Radiation Oncology.

Ms Della Thomas, Data Manager, Womens Health Unit.

Mr David Rhodes, Director Allied Health, WVH.

Mr Peter Field, Member Oncology Services Consumer Group

Dr Bruce Shadbolt, Director, Epidemiology & Population Health.

Ms Norma Briscoe, ACT Cancer Registry.

Mr Paul Currie, Data Manager, Palliative Care.

Dr John Eather Division of General Practice

Ms Kate Burns, Project Officer, Cancer Strategic Plan

Rehabilitation & Extended Care:

Chair: Mr Russell McGowen, Member Oncology Services Consumer Group.

Ms Sheila Stevenson, ACT Cancer Society.

Ms Trish Towning, Executive Director, ACT Respite Care.

Mr George Redfern, Member Oncology Services Consumer Group.

Ms Ester Cutts, HACC representative.

Sr Lyn Bower, Oncology Nurse Specialist, Community Nursing.

Ms Jo Nicholas. Services Policy & Planning

Ms Ilya Lovric, Social Worker, Oncology Services, WVH.

Dr David Jarvis GP, Division of General Practice.

Ms Kate Burns, Project Officer, Cancer Strategic Plan

Palliative Care Working Party:

Chair: Ms Karen Sorenson, ACT Cancer Society.

Dr Tony Sangster, Division of General Practice/ CMO ACT Hospice

Sr Berenice, Director Of Nursing, ACT Hospice.

Ms Bev McQuaide, Volunteer Coordinator, ACT Hospice & Palliative Care Society.

Dr Elizabeth O'Leary, Acting Assistant Clinical Director, Calvary Hospital.

Mr Rys Ollerenshaw, Policy & Planning , ACT Health.

Ms Jenny Satrapa, Member Oncology Services Consumer Group.

Sr Brad Smith, CNC, Oncology Ward, WVH.

Mr Roger Stonham, Member Oncology Services Consumer Group.

Dr Ken Sunderland, Radiation Oncologist, WVH.

Ms Shirley Sutton, Director Palliative Care, Community Nursing Services

Sr Myra Troy, CNC Home Based Palliative Care Program,.

Ms Victoria Jones, Oncology Social Worker, WVH

Project Process: August 1994 – March 1996

Stage 1 Aug 1994 - Jan 1995

- Establishment of project
- Literature search
- Clarification of some underlying key concepts
  - area health management
  - participation
  - accountability
  - outcomes management

- **First progress report to the Commonwealth: Dec 1994**
- detailed outline of program objectives/performance indicators
- broad outline of cancer issues/structural and financial impediments
- mapping of cancer needs
- description of cancer population and service activities

- **Formation of Reference Group:**

Terms of Reference

The Reference Group will provide the major source of expertise and advice to the Strategic Plan including:

- *Monitoring the process of development and implementation of the plan;*
- *Supporting active consultation on the development and implementation of the project with ACT Health service providers, private health practitioners, relevant non-government organisations and the ACT community*
- *Providing expertise and advice, as required, in response to various issues raised*
- *Advise on issues which have the potential to promote or hinder the achievement of the project; and*
- *Establish sub-groups to examine specific issues in closer detail, as required.*

Stage 2: Feb 1995 - July 1995:

Formation of working parties along Care Continuum

- *Health Promotion/Prevention*
  Goal: Develop a health literacy model for cancer

- *Diagnosis & Early Intervention*
  Goal: Develop an Issues Paper

- *Treatment Working Party*

Goals: develop and oversee the implementation plan for a cancer data collection system

- ***Rehabilitation & Extended Care***
  Goal: To develop an issues paper

- ***Palliative Care Working Party***
  Goal: Develop a Business Plan for palliative care.

The working parties were supported by the project officer, with appropriate government reports, and research literature. Ongoing clarification of key issues, data needs and emerging research questions was discussed by the Reference Committee.
Their work is described in detail in the following section of the paper.

- Developing working party recommendations

- Drafting Strategic Plan
  working parties identified goals, objectives and key activities from their individual areas

Second Progress Report to the Commonwealth: Aug 1995

- Preparations for Joint Working Party Planning Day

Stage 3 Sept 1995 - Feb 1996

- Development of a Strategic & Implementation Plan for Cancer Services

Third Progress Report to the Commonwealth Oct 1995.

- Exploration of proposed federal/state governments changing health roles

- Exploration of Purchaser Provider Model

- Continuing literature search and editing of draft reports from working parties

Final report to the Commonwealth Mar 1996 Discussion Paper.

Formal presentations of this project.

- 3 September 1994 Clinical teams (Includes medical, nursing and social work members). Introduction to concept of area health management and the national health policy.

- February 1995 Outline of cancer issues.

- July 1995 Summary of reports from working parties.

- Nursing teams;

-
- July 1995 team meetings Outline of strategic plan

- November 1995 – team meetings Outline of strategic plan.

Social Work:
- Sept – Dec 1994 Monthly meetings to background hospital social workers providing cancer services.
- Discussion of project with social workers involved in cancer service provision throughout hospital throughout 1995.
- Discussions at Oncology Team meetings throughout 1995

Oncology Services Network:

- Formal Presentation – Introduction to Project September 1994
- Progress reports quarterly to network meeting.
- Formal presentation of Plan September 1995.
- Implementation Issues – March 1996

Oncology Services Consumer Group

- Formed a reference group to discuss participatory approaches Aug – Oct 1994.

- Monthly reports provided throughout the project. Copies of all deliverables tabled as they were presented to the Commonwealth.

- Workshop run in June 1995 to present strategic context.

Health Executives:

- ACT Health; May 1995 Outline of Strategic Approach.

- Hospital Executive Committee; June 1995 Outline of Strategic Planning for Cancer Services in the ACT

- ACT Health; September 1995 Presentation of the Needs Analysis of Cancer Services in the ACT.

Informal Discussions.
- All members of the reference committee were individually briefed – usually 1 –1.5 hours. Most of the working party members were also individually briefed.
- Ongoing contact with range of colleagues, consumers and health administrators involved in the project to clarify issues, concepts and direction of the project.
- This involved many hours of discussion and their advice and support was critical to its evolution.

Appendix B:

Summary of Issues to be addressed in the delivery of cancer services in the ACT

These issues have been discussed in detail in the first section of this paper.
In many instances the development of clinical audit instruments could provide the basis for quality assurance and outcome measurements for evaluating service provision.

Cancer Services:

Woden Valley Hospital/Calvary Hospital/John James

Composition of Health teams:
Medical Practitioners: surgeons, medical and radiation oncologists, haematologists,palliative care physicians, GP's
Health Professionals: nurse practitioners, social workers, psychologists, physiotherapistsspeech/occupational therapists, complementary therapists
Technical support: Health Promotion services, epidemiologists and clinical researchers health policy analysts.

reference: Expert Advisory group on Cancer to the Chief Medical officers of England & Wales: "*A Policy Framework for Commissioning Cancer Services.* " May 1994.

Level of service provision:
- cancer treatment – cancer registries.
- identify gaps in service provision
- address psycho–social needs
- after hours access
- palliative care

Information provision:
- review material
- informed decision making
- information for carers

Research:
- Identification of psycho–social need

Case Management
- Primary care and specialist
- Comprehensive care – multidisciplinary and complementary services
- Physiotherapy/speech therapy service provision

Patient information/Community education
- Orientation to the health system
- Modern pain theories
- social psychology theories of health behaviour
- Consumer guides to treatment options of major tumor sites
- targeted programs to encourage informed decision making
- Community organisations and cancer care

Professionl Education

NHMRC clinical guidelines

Clinical programs on social psycholog theories of health behaviour

Quality assurance
-multi–disciplinary clinics
-evidence based protocols
- participation in multi–centre trials
- clinical audits

Primary Prevention Programs
- Evaluation of current breast and cervical screening progams
- education programs on benefits of above programs
- screening practices of ACT GP's

Health Promotion:

ACT Cancer Society/ACT Health/GP's

Health teams
ACT Cancer Society, Oncology Community Network,
Support Teams
Health Advancement, Division of G.P.'s

Reference: National Health & Medical Research Council. "*Health Australia. Promoting Health in Australia.*" Dec 1995.

Summary of Issues

Primary prevention programs
– Smoking/ skin protection

Community education programs:

- attitudes and beliefs towards cancer prevention and treatment
- limitations and benefits of screening
- information on cancer care issues for family and friends
- bereavement education

Community Support Programs

Agencies
Regional Community Services, ACT Respite Care, Carers Association, HACC, Mobile Rehabilitation Unit, Community Options, ACT Cancer Society

Transport **Respite Care** **Home Help**

Mobile Aids **Child Care** **Support Groups**

Reference: House of Representative Standing Committee on Community Affairs *HOME But Not Alone.* July 1994.

Health Policy:

Expert Cancer Advisory Group
ACT Council Of Social Services
Oncology Services Consumer Group

– Consumer and community participation

– Convalescent Care

– Income support for cancer patients

– Health insurance

Agencies Suggested as Responsible for Implementation of Cancer Plan

(NB numbering refers to goal, objective and action as outlined in the Implementation Plan – Appendix C. eg 1.1.2 refers to goal 1, objective 1, action 2.)

A: ACT Health:

Oncology Services: Woden Valley Hospital/Calvary/John James

1.1.2. Ensure timely access to comprehensive cancer medical treatment.

1.1.3. Examine the need for a paediatric oncology service with regard to current and future service needs and cost-effectiveness.

1.1.4. Identify and continue to develop services to meet the physical, psychological and social needs of people living with cancer.

1.2.1. Review currently available cancer material and ensure it complys with current standards.

1.3.5.Develop audit programs for health teams to evaluate their communication effectiveness.

2.1.1. Develop strategies to enhance integration of public and private sector cancer services in the ACT and the region.

2.1.3. Ensure the psycho-social needs of patients are addressed from diagnosis, during hospitalisation, and a following discharge.

2.2.1. Provide information and develop programs to enable all patients to actively participate in informed decision making about their treatment.

2.2.4. Establish multi-disciplinary clinics for the management of patients with lung, breast cancer, colorectal and gynaecological cancers.

2.2.5. Implement, review and update evidence based treatment protocols in all cancer services.

2.2.6. Establish a hospital-based cancer registry.

2.3.3. Encourage participation in multi-centre trials and promote the value of such trials to the community.

2.1.2. Collect accurate data abotut the gaps and deficiencies in service provision.

2.1.4. Ensure that the resourcing of cancer services allows for adequate support for staff in all disciplines (for example, through debriefing and peer support), consistent with occupational health and safety standards.

2.2.8. Develop a community education program and information network about modern pain theories including symptom managment and about available resources.

2.2.9. Increase access to expert pain management for people living with cancer.

2.4.5. Develop education programs about the special needs of cancer patients for coordinators and support staff of community agencies providing support to people living with cancer, and their families or carers.

3.1.1 Examine opportunities for improved case management between primary care and specialist cancer services.

3.1.6. Investigate the value of patient-held records in enhancing contnuity of care.

Paediatric Services:

1.1.3. Examine the development of a paediatric oncology service in regard to current and future needs and cost effectiveness.

Professional Services: Allied Health/Nursing

2.1.2. Collect accurate data about the gaps and deficiencies in service provision.

3.1.2. Ensure services provided by allied health professionals on an outpatient basis continue to be available to cancer patients on the basis of identified need.

Social Work Department

1.1.4. Identify and continue to develop services to meet the physical, psychological and social needs of people living with cancer.

1.1.7. Develop a bereavement education strategy and service network to improve community understanding of grief and loss, and access to support services.

1.3.4. Develop continuing education programs for health service providers to ensure effective communication skills, and enhance knowledge about the appropriateness, timeliness and consistency of information being provided to people living with cancer.

1.3.6. Enhance community understanding of cancer treatments and services.

2.1.2. Further develop and evaluate programs that assist patients to orient themselves to the health system in general and the hospital system in particular.

2.1.3. Evaluate current screening programs for cancer of the breast and cervix for effectiveness in reaching target populations and compliance with guidelines.

2.1.4. Expand public education campaigns to educate women in the community about the benifits of screening for cancer of the breast and cervix and to target those most at risk.

2.3.3. Encourage participation in multi–centre trials and promote the value of such trial to the community.

2.3.5. Encourage research into the psycho–social needs of people living with cancer in the ACT.

2.4.1. Encourage the development of continuing education programs to enhance health professionals' understanding of theories of health behaviour.

Psychology Department

1.1.4. Identify and continue to develop services to meet the physical, psychological and social needs of people living with cancer.

1.1.5. Identify gaps in and enhance access to comprehensive pallative care services in the community.

2.1.2. Collect accurate data about the gaps and deficiencies in service provision.

School of Nursing

2.1.2. Collect accurate data about the gaps and deficiencies in service provision.

2.1.4. Ensure that the resourcing of cancer services allows for adequate support for staff in all disciplines (for example, through debriefing and peer support), consistent with occupational health and safety standards.

2.3.3. Encourage participation in multi–centre trials and promote the value of such trial to the community.

2.4.1. Encourage the development of continuing education programs to enhance health professionals' understanding of theories of health behaviour.

3.2.3. Develop further opportunities for nurse education in cancer care.

Pain Clinic

2.2.8. Develop a community education program and information network on modern pain theories including symptom management and available resources.

2.2.9. Increaseaccess to expert pain management fr people living with cancer.

2.4.1. Encourage the development of continuing education programs to enhance health professionals' understanding of theories of health behaviour.

Health Promotion Services

1.2.2. Futher develop and evaluate programs that assist patients to orient themselves to their health system in general and the hospital system in particular.

2.2.1. Provide information and develop programs to enable all patients to actively participate in informed decision making about their treatment.

2.2.8. Develop a community education program and information network about modern pain theories including symptom management and about available resources.

2.4.1. Encourage the development of continuing education programs to enhance health professionals' understanding of theories of health behaviour.

2.4.2. Monitor any changes in health policy which impact on the non-government community agency sector.

4.1.1. Implement living with cancer information programs for the special needs of children, carers, migrants, and Aboriginal and Torres Strait Islander peoples.

Palliative Care Agencies

1.1.5. Identify gaps in and enhance access to comprehensive pallative care services in the community.

1.1.6. Monitor palliative care service provision to ensure timely access for all those in need taking particular account of migrant and Aboriginal and Torres Strait Islander people.

1.1.7. Develop a bereavement education strategy and service network to improve community understanding of grief and loss, and access to support services.

2.2.8. Develop a community education program and information network about modern pain theories including symptom management and about available resources.

3.1.4. Ensure appropriate support services are designed and integrated into a seamless pallitive care service.

Canberra Clinical School

2.3.3. Encourage participation in multi-centre trials and the promote the value of such trials to the community.

2.3.4. Encourage participation in multi-disciplinary research.

2.3.5. Encourage research into the psycho-social needs of people living with cancer in the ACT.

2.4.1. Encourage the development of continuing education programs to enhance health professionals' understanding of theories of health behaviour.

4.2.2. Establish professional education programs to enhance communication about cancer issues with groups who have special needs.

Div of Public Health

1.1.1. Implement the ACT Health, Goals and Targets for the reduction in the incidence and mortality of cancer.

1.1.5. Identify gaps in and enhance access to comprehensive pallitive care services in the community.

1.2.5. Encourage informed community debate about limitations and benefits of screening for cancer.

2.2.8. Develop a community education program and information network about modern pain theories including symptom management and about available resources.

2.3.5. Encourage research into the psycho-social needs of people living with cancer in the ACT.

3.1.7. Ensure that people living with cancer are able to participate in the planning of cancer services.

3.2.2. Distribute practice guidelines on cancer screening and management , such as those developed by the National Health and Medical Research Council or locally, to general practitioners.

Epidemiology and Population Health

2.2.6. Establish a hospital-based cancer registry.

2.3.1. Develop a coordinated and integrated information base to inform policy, planning and practice decisions, using population-based and hospital based registrations and other special data systems, taking into account privacy issues.

2.3.2. Cooperate with national and international disease specific registries.

2.3.4. Encourage participation in multi-disciplinary research.

3.1.1. Examine opportunities for improved case management between primary care and specialist care services.

3.1.3. Develop a database capable of identifying the community service support needs of people living with cancer.

3.2.1. Survey the cancer screening practices of general practitioners in the ACT.

ACT Community Care

2.4.2. Monitor any changes in health policy which impact on the non-government community agency sector.

3.1.3. Develop a database capable of identifying the community sevice support needs of people living with cancer.

Women's Health Services

1.2.3. Evaluate current screening programs for breast and cervix for effectiveness in reaching target populations and compliance with national guidelines.

1.2.4. Expand public education campaigns to educate women in the community about the benefits of screening for cancer of the breast and cervix and to target those most at risk.

3.2.1. Survey the cancer screening practices of general practitioners in the ACT.

Health Advancement Services

2.2.1. Provide information and develop programs to enable all patients to actively participate in informed decision making about their treatment.

2.2.8. Develop a community education program and information network on modern pain theories including symptom management and about available resources.

1.3.5. Develop audit programs for health teams to evaluate their communication effectiveness.

B: Non Government Agencies/ Consumer Bodies

4.1.1. Implement living with cancer programs to meet the special needs of children, carers, migrants, and Aboriginal and Torres Strait Islander people.

4.1.2. Establish professional education programs to enhance communication about cancer issues with groups who have special needs.

ACT Cancer Society

1.1.7. Develop a bereavement education strategy and service network to improve community understanding of grief, loss, and access to suppot services.

1.2.1. Review currently available cancer education material and ensure it complies with current standards.

1.2.5. Encourage informed community debate about limitations and benefits of screening for cancer.

2.2.8. Develop a community education program and information network on modern pain theories including symptom management and about available resources.

1.3.1. Encourage informed community debate around attitudes and beliefs regarding cancer.

1.3.2. Provide information to carers, relatives and friends on relevant cancer care issues.

1.3.6. Enhance community understanding of cancer treatments and services.

1.3.7. Conduct regular education campaigns to inform the public about early warning symptoms of cancer.

4.1.1. Implement living with cancer programs to meet the special needs of children, carers, migrants, and Aboriginal and Torres Strait Islander people.

Oncology Services Network

1.3.3. Develop education programs on cancer care issues for community based agencies.

2.4.2. Consolidate information on community organisations and agencies which provide assistance to cancer patients.

2.4.5. Develop education programs about the special needs of cancer patients for coordinator and support staff of community agencies providing support to people living with cancer, and their families and carers.

ACT Respite Care

1.3.3. Develop education programs on cancer care issues for community based agencies.

Carers Association of the ACT

1.3.3. Develop education programs on cancer care issues for community based agencies.

Oncology Services Consumer Group (OSCG)

3.1.7. Ensure that people living with cancer are able to participate in the planning of cancer services.

2.4.1. Encourage the development of continuing education programs to enhance health professionals' understanding of theories of health behaviour.

C: Professional Bodies/Universities

Division of GP's

2.2.7. Develop a continuing education program about the management of cancer pain for general practitioners.

3.1.1. Examine opportunities for improved case management between primary care and specialist cancer services.

3.1.5. Encourage the formal involvement of general practitioners on the Boards of community services agencies.

3.2.1. Survey the cancer screening practices of general practitioners in the ACT.

4.1.2. Establish professional education programs to enhance communication about cancer issues with groups with special needs.

Professional Colleges & Associations

1.3.4. Develop continuing education programs for service providers to ensure effective communication skills, and knowledge of the appropriateness, timeliness and consistency of information being provided to people living with cancer.

University of Canberra

3.2.3. Develop further opportunities for nurse education in cancer care.

D: Federal Agencies

Australian Health Ministers Advisory Council (AHMAC)

1.1.8. Recommend to the federal government that the guidelines for the Home and Community Care Program be expanded to include convalescent care for palliative care clients.

Department of Social Security

4.1.3. Examine ways in which the employment, insurance, superannuation and income support needs for people living with cancer can be addressed.

ACOSS:

4.1.3. Examine ways in which the employment, insurance, superannuation and income support needs for people living with cancer can be addressed.

E: Proposed Umbrella Organisation

Expert Cancer Advisory Group

1.1.6. Monitor palliative care service provision to ensure timely access for all those in need, taking particular account ofthe needs of migrant and Aboriginal and Torres Strait Islander people.

1.3.3. Develop education programs on cancer care issues for community based agencies.

1.3.4. Develop continuing education programs for health service providers to ensure effective communication skills, and enhance knowledge about the appropriateness, timeliness and consistency of information being provided to people with cancer.

2.1.2. Collect accurate data about the gaps and deficiencies in service provision.

2.1.4. Ensure that the resourcing of cancer services allows for adequate support for staff in alldisciplines (for example, through debriefing and peer support), consistent with occupational health and safety standards.

2.1.5. Ensure that sufficient cancer services are provided, taking into account changes in technology and need.

2.2.2. Establish a committee to recommend action, based on monitoring and surveillance of data for cancer care and control.

2.2.3. Establish expert groups to develop locally applicable, evidence-based practice guidelines for screening, early detection, management and pallation of different cancers.

2.2.9. Increase access to expert pain management for people living with cancer.

2.3.1. Develop a coordinated and integrated information base to inform policy, planning and practice decisions, using population-based and hospital-based *cancer registration and other special data systems, taking into account privacy issues.*

2.4. 2. Monitor any changes in health policy which impact on the non-government community agency sector.

2.4.4. Monitor the provision of palliative care services to ensure they are appropriate and effective.

3.1.6. Investigate the value of patient-held records in enhancing continuity of care.

3.1.7. Ensure that people living with cancer are able to participate in the planning of cancer services

4.1.1. Implement living with cancer programs to meet the special needs of children, carers, migrants, and Aboriginal and Torres Strait Islander people.

4.1.2. Establish professional education programs to enhance communication about cancer issues with groups with special needs.

4.1.4. Examine ways of addressing the information and service needs of people with cancer who live in rural areas of the ACT region.

Appendix C: Implementation Plan

Implementation will be undertaken by service agreements with the appropriate agencies aided by a Cancer Expert Advisory Group. For those agencies funded outside ACT Health, the support of the professional bodies will be sought to achieve the changes nominated.

Professional support will be provided by the Division of Population Health for scientific and evidence based activities. Program development to assist fulfilment of service agreements will be provided by the Health Outcomes Policy and Planning branch.

Goal 1: Accessible, appropriate and timely cancer services that recognise the consumer's right to choose and participate in all treatment services.

Objective 1.

To ensure that appropriate services are available to patients with cancer and their carers.

Actions:

1. *Implement the ACT Health Goals and Targets for the reduction in the incidence and mortality of cancer.*
2. *Ensure timely access to comprehensive cancer medical care.*
3. *Examine the need for a paediatric oncology service with regard to current and future service needs and cost-effectiveness.*
4. *Identify and continue to develop services to meet the physical, psychological and social needs of people living with cancer.*
5. *Identify gaps in and enhance access to comprehensive palliative care services in the community.*
6. *Monitor palliative care service provision to ensure timely access for all those in need, taking particular account of the needs of migrant and Aboriginal and Torres Strait Islander people.*
7. *Develop a bereavement education strategy and service network to improve community understanding of grief and loss, and access to support services.*
8. *Recommend to the Federal government that the guidelines for the Home and Community Care Program be expanded to include convalescent care for palliative care clients.*

Goal 1: Accessible, appropriate and timely cancer services that recognise the consumer's right to choose and participate in all treatment services.

Objective 2.

To provide up to date, relevant and credible information across the care continuum.

Actions:

1. *Review currently available cancer education material and ensure it complies with current standards.*

2. *Further develop and evaluate programs that assist patients to orient themselves to the health system in general and the hospital system in particular.*

3. *Evaluate current screening programs for cancer of the breast and cervix for effectiveness in reaching target populations and compliance with national guidelines.*

4. *Expand public education campaigns to educate women in the community about the benefits of screening for cancer of the breast and cervix and to target those most at risk.*

5. *Encourage informed community debate about the limitations and benefits of screening for cancer.*

Goal 2: Services are effective, efficient and of high quality.

Objective 1.

To develop an integrated comprehensive cancer care service for the ACT with appropriate outreach to the SE Region of NSW.

Actions:

1. *Develop strategies to enhance integration of public and private sector cancer services in the ACT and the region.*

2. *Collect accurate data about the gaps and deficiencies in service provision.*

3. *Ensure that the psycho-social needs of patients are addressed from the time of diagnosis, during hospitalisation and following discharge.*

4. *Ensure that the resourcing of cancer services allows for adequate support for staff in all disciplines (for example, through debriefing and peer support), consistent with occupational health and safety standards.*

5. *Ensure that sufficient cancer services are provided, taking into account changes in technology and need.*

Objective 2

To ensure best practice and assess the outcomes of interventions.

Actions:

1. *Provide information and develop programs to enable all patients to actively participate in informed decision making about their treatment.*

2. *Establish a committee to recommend action, based on monitoring and surveillance data for cancer care and control.*

3. *Establish expert groups to develop locally applicable, evidence–based practice guidelines for screening, early detection, management and palliation of different cancers.*

4. *Establish multi–disciplinary clinics for the management of patients with lung, breast cancer, colorectal and gynaecological cancers.*

5. *Implement, review and update evidence based treatment protocols in all cancer services.*

6. *Establish a hospital–based cancer registry.*

7. *Develop a continuing education program about the management of cancer pain for general practitioners.*

8. *Develop a community education program and information network about modern pain theories including symptom management and about available resources.*

9. *Increase access to expert pain management for people living with cancer.*

Objective 3:

To facilitate the application of research to improve standards of care.

Actions:

1. *Develop a coordinated and integrated information base to inform policy, planning and practice decisions, using population–based and hospital–based cancer registrations and other special data systems, taking into account privacy issues.*

2. *Co–operate with national and international disease specific registries.*

3. *Encourage participation in multi-centre trials and promote the value of such trials to the community.*

4. *Encourage participation in multi-disciplinary research.*

5. *Encourage research into the psycho-social needs of people living with cancer in the ACT*

Objective 4:
To enhance the quality of life of people living with cancer, and of their families and friends.

Actions:

1. *Encourage the development of continuing education programs to enhance health professionals' understanding of theories of health behaviour.*

2. *Monitor any changes in health policy which impact on the non-government community agency sector.*

3. *Consolidate information about community organisations and agencies which provide assistance to cancer patients.*

4. *Monitor the provision of palliative care services to ensure they are appropriate and effective.*

5. *Develop education programs about the special needs of cancer patients for coordinators and support staff of community agencies providing support to people living with cancer, and their families or carers.*

Goal 3: Continuity of patient care is guaranteed.

Objective 1

To address identified service gaps in multidisciplinary care.

Actions:

1. *Examine opportunities for improved case management between primary care and specialist cancer services.*

2. *Ensure services provided by allied health professionals on an outpatient basis continue to be available to cancer patients on the basis of identified medical need.*

3. *Develop a database capable of identifying the community service support needs of people living with cancer.*

4. *Ensure appropriate support services are designed and integrated into a seamless palliative care service.*

5. *Encourage the formal involvement of general practitioners on the Boards of community services agencies.*

6. *Investigate the value of patient–held records to in enhancing continuity of care.*

7. *Ensure that people living with cancer are able to participate in the planning of cancer services.*

Objective 2

To improve the teaching of cancer control and management at undergraduate and postgraduate levels.

Actions:

1. *Survey the cancer screening practices of general practitioners in the ACT.*

2. *Distribute practice guidelines on cancer screening and management, such as those developed by the National Health and Medical Research Council or locally, to general practitioners.*

3. *Develop further opportunities for nurse education in cancer care.*

Goal 4: Services are culturally appropriate and responsive to special needs.

Objective:

To ensure that cancer care and control services are sensitive to the needs of particularly disadvantaged groups, culturally appropriate and accessible.

Actions:

1. *Implement 'living with cancer' information programs to meet the special needs of children, carers, migrants, and Aboriginal and Torres Strait Islander people.*

2. *Establish professional education programs to enhance communication about cancer issues with groups who have special needs.*

3. *Examine ways in which the employment, insurance, superannuation and income support needs of people living with cancer can be addressed.*

4. *Examine ways of addressing the information and service needs of people with cancer who live in rural areas of the ACT region.*

Appendix D: National Goals & Targets for health prevention[56]

Primary Goal: Reduce the incidence of and mortality of cancer

Indicator: Incidence of cancer of the *trachea, bronchus and lung*

National baseline and target:

	Baseline (1990)	Target (2000)
males	Not set	Not set
Females	Note set	Not set

Indicator: Death rate for cancer of the *trachea, bronchus and lung*

National baseline and target:

	Baseline (1990)	Target (2000)
Males	Not set	Not set
Females	Not set	Not Set

Indicator Incidence of *melanoma of the skin*

National baseline and target:

	Baseline (1990)	Target (2000)
Males	33.1	32.4
Females	28.2	27.6

Indicator Death rate for *melanoma of the skin*

National baseline and target:

	Baseline (1990)	Target (2000)
Males	4.7	4.5
Females	2.7	2.6

Indicator Incidence of *non-melanocytic skin* cancer

National Baseline and Target

	Baseline (1990)	Target (2000)
Males	1,187	32.4
Females	769	27.6

Indicator Death rate for *non-melanocytic skin* cancer

National Baseline and Target

	Baseline (1990)	Target (2000)
Males	1.6	1.7
Females	0.4	0.3

Indicator Incidence of cancer of the *cervix*

National Baseline and Target

	Baseline (1988)	Target (2000)
Women	17.2	17.2

Indicator Death rate for cancer of the *cervix*

National Baseline and Target

	Baseline (1991)	Target (2000
Women	3.9	3.3

Indicator Incidence of breast cancer

National Baseline and Target

	Baseline (1988)	Target (2000)
Women	62.3	Not set

Indicator	Death rate for breast cancer		
National Baseline and Target		Baseline (1992)	Target (2000)
	Women	19.6	17.6

Indicator	Incidence of colorectal cancer		
National Baseline and Target		(1988)	(2000)
	Males	44.0	Not set
	Females	30.5	Not set

Indicator	Death rate for colorectal cancer		
National Baseline and Target		(1988)	(2000)
	Males	20.1	Not set
	Females	13.6	Not set

Indicator	Incidence of prostate cancer		
National Baseline and Target		(1988)	(2000)
	Males	48.7	Not set

Indicator	Death rate of prostate cancer		
National Baseline and Target		(1992)	(2000)
	Males	19.2	Not set

Goal: Ensure high levels of screening for early detection of cancers where there is a scientifically demonstrated benefit at acceptable cost.

Indicators:	Proportion of persons screened for breast cancer Proportion of persons screened for cancer of the cervix		
		Baseline	Target
National Baseline & Target	Women	Not set	Not set

Goals & Targets in cancer treatment

Goal: **Reduce morbidity and mortality from cancer**

Indicators: Five year survival rate for cancer of the trachea, bronchus and lung

Five year survival rate for melanoma of the skin
" " " " non-melanocytic skin cancer
" " " " cancer of the cervix
" " " " breast cancer
" " " " colorectal cancer
" " " " prostate cancer

Disability adjusted survival rate for cancer of the trachea, bronchus and lung
" " " " melanoma of the skin
" " " " non-melanocytic skin cancer
" " " " cancer of the cervix
" " " " breast cancer
" " " " colorectal cancer
" " " " prostate cancer

Patient satisfaction with treatment for cancer of the trachea, bronchus and lung
" " " " melanoma of the skin
" " " " non-melanocytic skin cancer
" " " " cancer of the cervix
" " " " breast cancer
" " " " colorectal cancer
" " " " prostate cancer

Note:

National Baseline Target		
	Males	Not set
	Females	Not Set

Goal: **Improve the quality and duration of life of women with breast cancer or heightened risk of breast cancer**

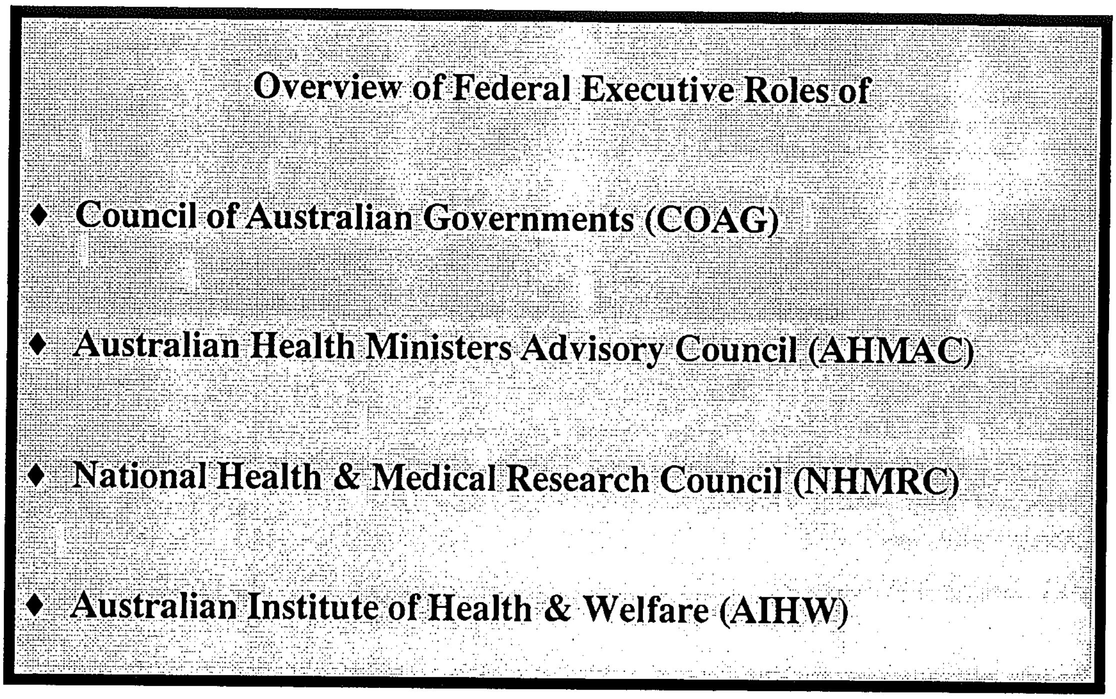
Indicator: Report by women of their participation in decision making about and satisfaction with
VALIDITY of this indicator is questionable

Goal: **maximise the quality of life, and dignity of death, of people with incurable cancer**

Indicator: to be developed by December 1995.

National targets: to be developed by December 1995

Appendix E: Overview of Federal Executive Roles



Overview of Federal Executive Roles of

- ♦ Council of Australian Governments (COAG)
- ♦ Australian Health Ministers Advisory Council (AHMAC)
- ♦ National Health & Medical Research Council (NHMRC)
- ♦ Australian Institute of Health & Welfare (AIHW)

Executive Action 1988 - 1995:

	Executive Action	Reports/Discussion Papers
	Council of Australian Governments (COAG)	
1994	Endorsed need for reform of health and & community services sector • Working Group on Health & Community Services	*National Health Strategy Publications 1992/93* Discussion Paper: *Health & Community Services: Meeting people's need better* Information paper: *Reform of Health & Community Servic - work in progress August 1995*
	Australian Health Ministers Advisory Council (AHMAC)	
1985	Better Health Commission	Report *Advancing Australia's Health 1985* Report *Looking Forward to Better Health 1986*
1987	Health Targets & Implementation Committee	Report *Health for All Australians 1988*
1989	National Better Health Program National Hospitals Statistics Project	
1992	Task Force on national health information	*Nutbeam Report 1993*
1993	National Health Information Agreement 1993-98 National Health Summit National Health Information Management Group	Report *Evaluation of the Better Health Program 1993* Discussion Paper *Towards a National Health Policy*
1994	Joint AHMAC/NHMRC Working Group National Health Policy Announced Better Health Outcomes Overseeing Committee (BHOOC) • National Health Information Management Group • Australian Health & Welfare Institute Monitoring Committee	Report *Better Health Outcomes for Australia 1994* *National Health Policy* *National Health Information Agreement Procedure M* *National Health Information Work Program 1994*
	National Health & Medical Research Council (NHMRC)	
1992	Working Party on Age issues in Mammography Screening	*Policy Statement on Mammography screening for women under 50 years of age*
1993	Report for the Organised Approach to Preventing Cancer of the Cervix	*Guidelines for the Management of Women with Screen Detected Abnormalities 1993*
1993	Health Care Committee	*Discussion paper on Ethics and Resource Allocation in Health Care 1986*
	• Expert Advisory Panel on Women & Mental Health	*Women and Mental Health Report 1990*
	Health Care Committee	*General Guidelines for medical practitioners on providing information to patients.* 1993
	Quality of Care & Health Outcomes Committee	*Guidelines for the Development and Implementation of Clinical practice Guidelines. 1995* *Clinical Practice Guidelines: The Management of Early Breast Cancer 1995* *A Consumers Guide to Early Breast Cancer 1995*
1991	**Australian Institute of Health & Welfare(AIHW)** National Cancer Statistics Clearing House National Minimum Data Set Review Committee	*National Health Data Dictionary 1993* *National Health Goals and Targets: Specification of data requirements Draft 1995*
	Commonwealth State Ministers for the Status of Women	
1994	Standing Committee	*The Price of Care* Report into Carers role in Australia

Council of Australian Governments (COAG)

The Council of Australian Governments (COAG) meeting in Hobart in February 1994 endorsed the need for reform of health and community services. A Task Force on Health and Community Services was appointed to steer the direction of reform and at its April meeting Ministers agreed to launch a major long–term reform of health and health–related community services. Health and Community Services Ministers have been charged with overseeing an Action Plan to implement reform. It is anticipated that this work will enable consideration of role and responsibilities at the first COAG meeting in 1996.

The proposals are looking at health and community services needs in terms of three broad care streams, within an overarching framework of population health. The broad care streams are general care (for people with simple walk–in, walk–out needs) acute care (mostly covering inpatient care and associated pre and post treatment) and coordinated care, covering those with complex and intense needs. The Commonwealth is currently looking at the abolition of all program boundaries, both within the federal department and in terms of Commonwealth–State boundaries.[57] (See appendix B for further details.)

Australian Health Ministers Advisory Council (AHMAC)

The Health Ministers through AHMAC have been systematically responding to the public health initiatives that have been evolving worldwide in the past 15 years. The technical problems of measurement including the collection of data are proceeding apace with the computer/information revolution which is providing tools for evaluation undreamt of twenty years ago. As a consequence the rhetoric of accountability in the health care system stands poised to become 'a phenomenon' for those aged over forty as the forces of history intersect in this arena.

The goals, targets and strategies being espoused through federal and state health planning systems are being addressed in four key areas to begin with; cardiovascular disease, cancers, injury and mental health. These four areas were chosen because of the recognition of their importance as underlying causes of ill health in Australia. In order to be effective they need to be linked to:

- the assessment of interventions
- identifying what works
- establishing a process to transfer best practice to actual practice
- identifying where best practice is occurring
- identifying impediments to best practice adoption[58]

Assessing the health status of the Australian population:

As signatories to the WHO Conventions Australia responded to the 1981 Global Health for All report by establishing in 1985 the Better Health Commission. Consisting of 12 part–time commissioners it was given the task of investigating and reporting on the current health status of the Australian population , identifying underlying health problems, and making recommendations to address these. Its terms of reference specifically drew attention to a broad approach to health and the needs of the at risk population groups. Its report[59] released in 1986 and based on extensive consultation nominated three priority areas – injury control, cardiovascular disease, and nutrition.

The Early Health Goals & Targets Activity

Following this report the Health Targets & Implementation Committee (1987) was established by AHMAC. This Committee comprised Commonwealth State/Territory government representatives and members of the Australian Institute of Health and the Consumers' Health Forum. The report it released in 1988 [60]attempted for the first time to refocus attention on a more positive vision of what health policy in Australia should aim to achieve.
Two principles were established:

- increasing the health status of all Australians
- and decreasing the inequalities in the health status between population sub–groups.

AHMAC in March 1988 agreed in principle to the establishment of a National Better Health Program. Considerable planning was undertaken with project teams developing strategic plans for five priority areas: injury prevention, the health of the elderly, primary prevention of lung and skin cancer and the secondary prevention of breast and cervical cancer, prevention of high blood pressure and nutrition. The recommended program reflected a mixture of diseases, risk factors, and population groups and was seen "*as a contested compromise resulting from lively, ongoing debates as to how the goals and objectives of the National Better Health Program were to be met.* "[61]The National Better Health Program was launched in Nov 1989 with matching Commonwealth/State funds and a budget of $41m for a 4 year period.

Review of the National Health Goals & Targets Activity

The Department of Health, Housing and Community Services commissioned a team headed by Professor Don Nutbeam to review the progress that had been made in promoting better health in Australia. The report [62]t analysed the progress that had been made to date in relation to the original goals and targets published in 1988, drew together the experience gained in both Australia and overseas during the decade, redefined the framework and suggested an implementation strategy. As already noted in our first chapter the Nutbeam Report was critical in identifying the political issue of mainstream health's lack of engagement in the health reform debate.

The impetus for national measurement identified in this review was strengthened by the 1993–98 Medicare Agreement whereby all states agreed to the development of a series of national health goals and targets by June 1994.[63] [64] [65][66][67][68]
Health Goals and Targets received their second political imprimatur in the forum conducted in April 1993 termed The National Health Summit whereby federal and state health ministers agreed to a framework for the development of a national health policy.[69] The Sunshine Statement as it has come to be called provided the framework for the national health policy embedded into which was the acknowledged of the need for structural reform and a joint AHMAC and NHMRC working group was established to develop a comprehensive set of goals and targets over time.

The Joint Australian Health Ministers Advisory Council (AHMAC) / National Health & Medical Research Council (NHMRC) Working Party

The Australian Cancer Society's Public Affairs and Behavioural Intervention Committee comprising a range of professionals in the field prepared a background document for the cancer implementation group of the National Goals and Targets and Strategies for Better Health Outcomes into the Next Century.

The focus of the report was to investigate current activities by Government and non-government organisations in the focus areas of all cancers. The report provides a most comprehensive overview of cancer control in Australia examining issues pertaining to epidemiology, data collection, health promotion and prevention, cancer management and support services identifying both many critical issues and gaps in service provision. The report also examined the health care system and the structural and financial impediments and disincentives to optimal cancer management and identified the infrastructure for achieving change.

This group had extensive Australia–wide consumer consultation (March – May) which resulted in the Report *Better Health Outcomes for Australia* [70] It was endorsed by AHMAC and in September 1994 its key tenets were incorporated in the national health policy .The National Health Policy delineated the principles for guiding priority setting and urged decisions be based on:

- *the best available data and evidence on population health issues and effectiveness of interventions;*
- *the degree of impact on population health status (as measured by mortality, morbidity, and quality of life);*
- *the availability and effectiveness of interventions;*
- *the cost to the community of the condition and its treatment and prevention; and*

- *the potential to reduce health inequalities.*[71]

Australasian Association of Cancer Registries (AACR)

Is the umbrella body for the population based cancer registries in Australia which provide comprehensive national data on cancer incidence and mortality survival showing trends over time and tumor profiles by age, sex, geographical location, and country of birth.

This group has been actively supporting efforts to obtain improved hospital based cancer registries to enable hospitals to quantify their cancer burden, examine treatment patterns and outcome by stage of disease and provide a source of core data for supplementation of other research issues.[72]

Regional health goals and targets cannot be determined without such a data collection.

National Institute of Health and Welfare (AIHW)

The NHMRC endorsed the concept of a national collection of cancer statistics in 1984 and the National Cancer Clearing Statistics House (NCSCH) under the supervision of the Australasian Association of Cancer Registries (AACR)and after various legislative enactments commenced activities in 1987.
The clearing house obtains data from the state cancer registries and has built an impressive body of reports thus enabling national trends to be obtained and permit much greater in depth discussion of cancer data in general. The national death index when it commences operation sometime this year will improve the quality assurance of all cancer registries around Australia through the linkage system to ensure duplication of recording no longer occurs.

The National Health Information Management Group who are responsible for overseeing the National Health Goals and Targets obtain secretariat and technical support from the AIHW.

National Health Information Agreement

The aim of the Agreement is to improve access to uniform health information by community groups, health professionals, government and non–government organisations.[73] Their key program is the development of a national health information work program. This is published annually and enables interested parties to share details of their activities.

Consultation were undertaken throughout 1994 with staff of health authorities and non–government organisations and individuals to assist in the development of the national health information framework, as part of the goal of establishing a National Health Information Plan.

National Health and Medical Research Council:

The objective of the National Health and Medical Research Council is to *advise the Australian community on the achievement and maintenance of the highest practicable standards of individual and public health and to foster research in the interests of improving those standards.*

The NHMRC has a number of principal committees amongst which are the Australian Health Ethics Committee, Health Advisory Committee, Medical Research Committee, the Public Health Research and Development Committee, and the Health Care Committee recently renamed the Quality of Care and Health Outcomes Committee.

Work of special significance to cancer care and control undertaken by the NHMRC in recent years was the Guidelines for the Management of Women with Screen Detected Abnormalities and their public health reports on passive smoking suntanning parlours, solaria and home–tanning equipment . The review and subsequent statements on mammography screening for women under 50 years of age and the interval of screening for cervical cancer screening provide authoritative guidelines.

Leadership has been given by the Health Ethics Committee to the idea of community consultation as part of community participation so that issues of access, equity and social justice were properly considered. The discussion paper issued by the NHMRC provides an excellent critique of the challenges of providing community participation that is not tokenism.[74]

Quality of Care and Health Outcomes Committee

This committee has been active in sponsoring broadly based community discussion on the issue of ethics and the allocation of resources, exploring the issues of women and their mental health, as well as developing general guidelines for medical practitioners on providing information to patients.

However, the most significant work has been the recently released *Guidelines for the Development and Implementation of Clinical Practice Guidelines.* The document proposes a methodology for developing clinical practice guidelines in Australia with the approach being seen as applicable to a variety of conditions and procedures. They emphasise that the term 'clinical' is intended to be inclusive of all health care providers, not just medical practitioners.
Accompanying the release of these guidelines was the first in the series *Clinical Practice Guidelines for The Management of Early Breast Cancer* together with its companion booklet providing a consumers guide. Professor Richard Smallwood, Chairman of the NHMRC in the opening remarks to the guidelines the point that the basic premise of the guideline development process is that they should be based on the best available evidence. "*The adoption of a multidisciplinary approach, involving all stakeholders, is a further key principle.*"

This national program it is hoped will not only assist practitioners make decisions about appropriate health care for specific clinical circumstances, but in providing consumers with similar comprehensive information about choices available in their treatment will improve the quality of care women receive in regard to their cancer treatment.

The NHMRC also allocates around $6 million a year in Commonwealth funds to cancer research through its three committees: Medical Research Committee; Public Health Research & Development Committee; and the Research & Development Grants Advisory Committee. Further support is indirectly provided through grant supports of such major research institutes as the Walter & Elide Hall Institute, The Howard Florey Institute, the Murdoch Institute for Research into Birth, the Baker Institute of Medical Research, and the Garvin Institute of Medical Research.[75]

NHMRC National Breast Cancer Centre

Has been funded by the Commonwealth for three years to contribute to breast cancer control in Australia. The terms of Reference make clear the Centre will not fund research but it "*is required to develop a comprehensive, national monitoring system and undertake evaluation of education strategies and programs to underpin its work.*"
The Mission and Goals of the Centre encourage a partnership with women, health professionals, cancer organisations, researcher and governments to "*improve cancer outcomes for women*".[76]
(See Appendix A for Terms of Reference and Goals)

Clinical Oncological Society of Australia (COSA)

National Breast Cancer Consensus Conference recommended that optimal standards be established for the diagnosis of impalable and palpable lesions. They also recommended national standardisation of clinical information to pathologists. It was noted that tumour characteristics presented more frequently with screen detected breast cancers which will impact on multidisciplinary therapy.

National Cancer Advisory Committee

Sponsored the National Conference on Hospital-Based Cancer Registries. This conference brought together clinicians and epidemiologists and data managers from the population based cancer registries around Australia to explore the question of establishing .hospital-based cancer registries. These are a critical component to monitoring and managing cancer and its outcomes and recommendation were made to the federal government supporting their establishment in the major public hospitals throughout the country.

The ACN undertook discussions with those medical faculties restructuring their medical degree courses to include a specific oncology component into their undergraduate curriculum.

In 1994 the ACN Breast Cancer Working party also produced an *Update on Breast Cancer* and 20,000 copies were printed and distributed; assisted in the preparation of the ACS/AGI *Colorectal Screening Guideline booklet* and undertook a seminar to discuss- *Issues for Cancer Management Toward and Beyond 2000* (Dec 1994) - facilitated by Prof Ken Donald. Guidelines are being prepared for Screening for Prostate Cancer.

Commonwealth/State Ministers for the Status of Women

A Progress Report [77]on Women as Carers by the Conference of Commonwealth/State Ministers for the Status of Women acknowledged the need for greater value to be placed on the social and economic benefit of unpaid care. The policy issues of the financial security of carers and employer policies on family leave are currently assumptions underpinning the social security system. The impact of breaks in employment and suspension of superannuation entitlements and contributions all effect carers long term security. The combined effect of a rise in the ageing population, increased incidence of chronic illness and early discharge from hospital care have all been highlighted in the report [78]commissioned by the Ministers.

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