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The Geelong Community’s Priorities and Expectations of Public Health Care

by

Stan Capp, B. Comm., M. Admin.

Submitted in fulfilment of the requirements for the degree of Doctor of Health Science, Deakin University, March 2001.
I certify that the thesis entitled “The Geelong Community’s Priorities and Expectations of Public Health Care”

submitted for the degree of Doctor of Health Science

is the result of my own research, except where otherwise acknowledged, and that this thesis in whole or in part has not be submitted for an award, including a higher degree, to any other university or institution.

Full Name  STANLEY BRUCE CAPP
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Acknowledgments

This thesis has been possible only through the assistance of a great many people who have supported me.

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Abstract

This thesis set out to achieve the following objectives:

(1) To identify the priorities and expectations that the Geelong community has of its public health care system.
(2) To determine if there is a common view on the attributes of a just health system.
(3) To consider a method of utilising the data in the determination of health care priority setting in Barwon Health.
(4) To determine a model of community participation which enables ongoing input into the decision making processes of Barwon Health.

The methodology involved a combination of qualitative and quantitative research. The qualitative work involved the use of focus groups that were conducted with 64 members of the Geelong community. The issues raised informed the development of the interview schedule that was the basis of the quantitative study, which surveyed a representative sample of 400 members of the Geelong community. Prior to reporting on this work, the areas of distributive justice, scarcity and community participation in health care were considered. The research found that timely access to public hospitals, emergency care and aged care services were the major priorities; for many people, the cost was less relevant than a quality service. Shorter waiting times and increased staffing levels were strongly supported. Increased taxes were nominated as the best means of financing the health system they sought. Community based services were less relevant than hospital services but health education was supported. An egalitarian approach to resource distribution was favoured although the community was prepared to discriminate in favour of younger people and against older people. There was strong support for the community to be involved in decision making in the public health care system through surveys or focus groups but very little support was given to priorities being determined by politicians, administrators and to a lesser extent, medical professionals.
Chapter 1
The Setting

1.1 Introduction

There are issues in life that are difficult to confront as they challenge the status quo and can cause anxiety, fear and guilt. There are other issues that seem so clear and where the answer is so obvious, that alternatives do not need to be considered. Australian health care has, since 1975, been placed in the second category. Medicare is a most highly prized social reform as it has ensured access to health care for all Australian residents. This has resulted in the community expecting that its health care should be provided by this system that ensures universal access at no or little cost to the consumer.

Medicare is Australia’s universal health insurance scheme. It was introduced in 1984 and builds on the first of these schemes, Medibank, which commenced in 1975. The cumulative effect of changes to Medibank by conservative federal Governments resulted in a need for its re-naming and a renewed commitment to its underlying objectives. The Health Insurance Commission (2001), a Government owned organisation that administers the enrolment and payment sides of Medicare, describes the objectives of Medicare as follows:

- to make health care affordable for all Australians;
- to give all Australians access to health care services with priority according to clinical need; and
- to provide a high quality care.

Medicare provides access to:

- free treatment as a public (Medicare) patient in a public hospital;
- free or subsidised treatment by practitioners such as doctors, including specialists, participating optometrists or dentists, for specified services only.

The public hospital system in Australia is a joint funding responsibility of Commonwealth, State and Territory Governments although the Commonwealth Government leaves the administration of public hospitals with the States and
Territories. The major source of funding the health system is through Commonwealth taxation that includes a specific Medicare levy.

Medicare is embraced as an important social reform as it has resulted in health care being available on the basis of clinical need to all Australians. Certainly there are perceptions about the timeliness of access and the ability to select a specific doctor when in hospital. This has meant a proportion of the community, currently about 40%, who elect to broaden their health care options by purchasing private health insurance. However, the majority of Australians rely upon Medicare to meet their health needs. The obvious response when asked about how a person’s health care needs should be dealt with is that Medicare should provide them.

The view that all health needs can, and indeed should be met from limitless community resources, is neither realistic nor rational in economic terms. It is not realistic because health care remains in many ways an inexact science and cures for all medical problems are yet to be found. This is regardless of the amount of funds available. It is not rational to consider resources as limitless, in Australia at least, due to the competing demands to share in the total wealth of the nation. While it may be appealing to consider an uncapped health budget, the likelihood of it happening appears remote.

The inevitable conclusion is that with a finite amount of funds to be invested and a demand for services that is unconstrained by cost, choices have to be made about how resources are allocated. This introduces the classic economic notion of scarcity and inevitably results in a need to prioritise and ration.

On the surface, the identification of priorities should be quite straightforward. There are some services that the community could reasonably be assumed to need more than others. All that is required is a means of determining what these are and how they can be most effectively provided. However, when priorities are applied in a practical way, lower priority areas take on an entirely different meaning. If a service is classified as being a low priority and this means that the service will be deferred or not performed at all, then the health care needs of a particular individual will not be met. This affects real people, who have real families, real needs and real expectations.
Rationing can not be done in isolation of community values, priorities and expectations. This thesis explores these issues in a way that challenges how things have developed in the Australian health care system. It seeks to gain an insight into the values that the community holds and the attributes that characterise a just and fair health system. A means through which the community can contribute to the debate is developed and this community participative approach presents some opportunities for considering how future decisions might be influenced.

1.2 The Setting of the Study

The location for this study is the community of Geelong, (Victoria, Australia) a major regional city and Victoria’s second largest metropolis after Melbourne, the State’s capital. The City of Greater Geelong has a population of approximately 190,000 people\textsuperscript{1} and is located 75 kilometres from Melbourne. It is sufficiently separate to have its own identity and forms a fascinating microcosm of Australia’s broader community. Similarities with the Australian population are seen in the age distribution of the Geelong population with an increasing number of persons aged over 65 years and a large cohort of so called “baby boomers” due to reach this age over the next 15 years. Geelong is the home of indigenous Australians for whom there is a strong representation through the Wauthourang community. There is a significant presence of persons with non-English speaking background and while this is predominantly European, increasing numbers of Asian immigrants are forming part of the community. Geelong is essentially an urbanised community but its proximity to the rural areas of Western Victoria and its traditional ties as a major regional centre for marketing primary production, combine to reflect the unique blend of country and city that typifies Australian society.

The Geelong community has strong connections to its major health icons - The Geelong Hospital, a 400 bed teaching hospital, and Grace McKellar Centre, a 450 bed facility for rehabilitation and aged care. These services, amongst others, are administered under the banner of Barwon Health. This organisation has defined, as a key part of its strategic planning process, the identification of the priorities and expectations that the Geelong

\textsuperscript{1} Data from the Australian Bureau of Statistics 1996 Census places the population at 173,042 but the Greater Geelong City Council estimate as at 2000 is 190,000
community has of its public health care system (Barwon Health, 1998). The study is therefore not only a piece of research into an internationally relevant subject; it is also a major contribution to developing a planning methodology for a significant health care organisation.

1.3 The Research Questions

The specific aims to be achieved from this work are to:

1) Identify the priorities and expectations that the Geelong community has of its public health care system.

2) Determine if there is a common view on the attributes of a just health system.

3) Consider a method of utilising the data in the determination of health care priority setting in Barwon Health.

4) Determine a model of community consultation which enables ongoing input into the decision making processes of Barwon Health.

1.4 The Methodology

The methodology adopted to address these aims involves a combination of qualitative and quantitative research. The qualitative work has been in the form of focus groups that have been conducted with members of the community from a range of different backgrounds. These focus groups explored participants’ general views about the public health care system. The issues raised informed the development of the interview schedule that formed the basis of the quantitative study. This latter study surveyed a representative sample of the Geelong community and examined the extent to which the broader community shared the views of the focus groups.

1.5 The Structure of the Thesis

Prior to reporting on this work, the preliminary chapters take a journey through a number of areas that will need to be understood to enable some meaningful analysis of the research outcomes. The first of these is in the area of distributive justice. While
some attention is given to understanding this concept in this opening chapter, a more critical evaluation of the values that drive the different models of justice is important in an understanding of how priorities and expectations are derived. This is presented in Chapter 2.

A second area of preliminary study is in exploring the notion of scarcity. Recognising that this is an international phenomenon driven by health systems that have finite resources, there remain issues of choice that must be addressed. The notion of rationing and the political implications of this are highlighted in this analysis that forms Chapter 3.

The final piece of academic theory notes the emergence of community participation as a major feature of western society. It is not only in the area of health care that models of community participation are being considered as it is becoming an increasingly important part of our everyday living. The need for people to be fully informed about anything that affects them is a reasonable expectation in the year 2000 and beyond.

The Ljubljana Charter (World Health Organisation, as cited in Coulter, 1999) on reforming health care highlights the role of the community in health decision making by advocating that: “The citizen’s voice and choice should make as significant a contribution to shaping health care services as the decisions taken at other levels of economic, managerial and professional decision making” (p. 219).

On a more local level, the Victorian State Government’s health policy (Australian Labor Party, Victorian Branch, 1999) states that consumers need to be more involved in decision making. The Government has indicated that it will ensure that community representation is a strong feature of appointments to the governing bodies of health care organisations. In the area of community health, a major review (Department of Human Services, Victoria, 2000) has recommended changing the governing bodies of these organisations to being partly appointed by the community. Changes to allow for a mix of elected and Government appointed members of Boards of Management have now been implemented. The previous process was for all appointments to be made by the Minister for Health.
There are numerous models of community participation that have been used throughout the world and these will be considered in a Chapter 4. There is no perfect formula that guarantees community participation will be effective, meaningful, timely and affordable. As a generalisation, the community has an imprecise level of knowledge about the health sector and to seek their involvement in decision making at anything other than the simplest level provides some challenges. The model that is adopted in this study builds on international experience that has been shown to be effective.

Given the theoretical and experiential context that Chapters 2, 3 and 4 provide, the chapters that follow develop the preferred model of community participation and further define the key issues that are to be discussed. The role of a specialist group that has acted as the study’s Steering Committee is of importance in this phase as it introduced a range of perspectives particularly from the clinical areas. The Steering Committee comprised five medical practitioners, two nurses and three academics, one of whom was also a nurse. Its role was to provide the project with timely advice about methodology, content and most importantly to ensure there was a practical relevance added to the issues raised. The Steering Committee met on two occasions. The first meeting addressed issues relating to focus groups and the second considered the preliminary results of the focus groups and how they informed the construction of the community survey. Several members of the Steering Committee also assisted in reviewing the interview schedule for the community survey and gave valuable advice.

The movement towards community participation is further discussed in Chapter 5 with its relevance to Geelong being emphasised. The dilemmas facing not only patients in need of care but also the professional clinicians who are involved in this process raise very serious ethical and social issues. Priority setting decisions are often taken by these clinicians in a total vacuum of knowledge about what the community thinks should happen. A practical example of these dilemmas will heighten the awareness of the critical need to undertake more research in this area so that the decision making process is more informed of community values and beliefs. It is in this context that the model of community participation for Geelong is determined.

Chapter 6 outlines the way that focus groups have been used in the study as a critical means to set the agenda for the more comprehensive quantitative work to follow. Focus
groups have been noted to offer "rich insights into people's views" (Coulter, 1999, p. 220) and while they can never be truly representative, can reflect a balance of views from groups based on age, gender, socio-economic status and ethnic background. The process of recruiting to these groups, the way that they worked and their key outcomes will be described in Chapter 6. These focus groups explored participants' general views about the public health care system and responded to specific questions designed to challenge the participants. The issues raised informed the development of the interview schedule that formed the basis of the quantitative study.

This quantitative study, the second piece of active research, is described in Chapter 7. This work surveyed a representative sample of the Geelong community and examined the extent to which the broader community shared the views of the focus groups. It was a single cross-sectional telephone interview study, conducted on a stratified random sample that included 400 residents of the area who were sufficiently fluent in English to be interviewed.

The final chapter analyses and discusses the results and considers the conclusions that can be reached. The conclusions are presented around the principal objectives of the study.

1.6 The Public Health Care System

The public health care system is a core focus of attention in this thesis. Before proceeding further, a few words need to be said about what is meant by this term. The terms public health care system and health care system will be used interchangeably. The need to differentiate it here is because the public system is characterised by the issue of scarcity that is less apparent in the non-public or private health care system. While there are imbalances in each system, there is a shortage in supply and an excess in demand in the public system whereas the private system has, if anything, an oversupply and a capacity to meet significant additional demand. The need to address the scarcity issue is thus far greater in the public system and this is the context for this study.

The public health care system, in its simplest form, includes all those services funded by Commonwealth and State Governments. Services regarded as public sector services
include public hospital and emergency care, community health services, dental services, aged care, home and community care, district nursing, mental health, immunisation, maternal and child health and other public health services. When priorities in public health care services are considered, they are being considered in the context of these defined areas.

While the contribution of Medicare towards medical fees is a Government responsibility, these services are traditionally regarded as being the domain of the private sector in that general practitioners and specialists do not see themselves typically as being on the Government's payroll. Other areas regarded as private health care include private hospitals and the large range of allied health professionals found outside the public sector.

In the Australian context, the public health care system is the health system that most people relate to with the specific exceptions of private hospitals and private clinicians. It is the system that people would know as Medicare and this has been discussed earlier in this chapter.

Placed on a more local level, the community is being asked to consider the type of health system that is available to them in the Geelong region. Questions need to ask how this meets their expectations, what are the areas of deficiency and if there is only a finite amount of funding, where are the areas that should be highly and lowly ranked?

1.7 Balancing Competing Demands

Before finalising this chapter, it is timely to put some further substance around the question of priority setting and why it is such an important factor in undertaking this research. Priority setting in the health sector is not a new phenomenon. However, in Australia there has been little analysis of the subject. This research aims to stimulate the discussion. There has been more explicit consideration overseas highlighted by two notable examples. The case of a 10 year old child who was refused funding for a second bone marrow transplant by the Cambridge and Huntingdon Health Authority (New, 1996), emphasises the dilemma of priority setting in the UK National Health Service. The second example involved another child, this time 7 years old, who was denied
treatment for his bone marrow transplant from the State of Oregon, USA (Citizens Health Care Parliament, 1988, as cited in Street & Richardson, 1992).

The tragedy of these two children heightened community and Government interest in priority setting on different sides of the world. In the first case, an anonymous donor financed some private care and death was delayed by possibly several months. The boy in Oregon succumbed as one would normally have expected. Both cases resulted in widespread community debate and resulted in differing responses. The Oregon example resulted in the most significant public policy change that has been recorded in favour of rationing. It ostensibly embraced community consultation to order the priorities but as will be discussed in Chapter 4, had some significant shortcomings.

The emphasis in each of these cases is on the rights of individuals to have the benefit of all of the services that are available, regardless of prognosis, cost or community values. They quite sharply focus on the potential for emotional and personal distress that a discussion on priority setting may evoke.

A review of Australian literature has been unable to identify any projects within Australia where the community has been involved in a formal process to the extent proposed in this study. As will be discussed later, there are several initiatives that have been taken internationally and have been used to assist in the refinement of this project.

Governments in Australia at Commonwealth, State and Local levels express commitments to consultative processes but there are few examples where this has achieved major reform. In the area of health financing within Victoria, decisions are taken on a broad policy level with, until recently, little regard for notions of community participation or involvement in establishing priorities. This is changing given the policies of the current Victorian State Government in favour of community participation. A more inclusive style of leadership is a cause of some optimism but it is still early days for a Government intent on social reform but in a fiscally responsible way. Although the potential for radical change seems slim, a more reformist Government committed to community participation may be attracted by a stronger community role in priority setting.
This thesis is about how a community can be involved in assigning priorities and in articulating its expectations. The eliciting of views of what determines a just health system produces a list of values that the community holds and places a philosophical perspective on the type of health system preferred. To then be able to utilise the data in a positive and constructive way indicates that the community’s view is acknowledged and should stimulate greater interest in future opportunities that could then be created.

The dilemma for those planning health services is that they have multiple and frequently conflicting options available to them. The weight that is placed on these options ultimately influences the decisions that are taken. The focus sharpens on the question of determining the sort of health system that is best provided given the social, political and economic environment that prevails. In seeking to explore the community’s view of what represents a just health system, the project will match the community’s views to the various models of distributive justice.

In coming to terms with what sort of a health system should be provided, the idea that it should be one which is fair, equitable and appropriate, would be a popular thesis. The right to receive care that reflects these principles in light of what is due or owed to persons is an example of justice being practised. Indeed, when care is determined in accordance with justified norms that structure the terms of social co-operation, it is described as distributive justice. When there are issues of scarcity and competition, it is not so easy to establish the most appropriate distribution because there are competing demands, which require judgements to be made and trade offs to be considered (Beauchamp & Childress, 1994).

This issue of social co-operation is important because it enables society to provide a better life for all than if individuals act totally independently of each other. The principles that are used to distinguish between the various social arrangements and to determine the proper distributive shares are the principles of social justice. Noted philosopher, John Rawls (1973), claims these define the appropriate distribution of the benefits and burdens of social cooperation.

Distributive justice is an appropriate starting point for a consideration of what features could characterise a just health care system. Given the diverse nature and backgrounds
of individuals, a broad community consensus on the most effective way of distributing justice would appear to be most unlikely. However, there is little evidence to validate such an assertion. There are several theories of justice that have been developed and each has a different perspective to offer and presents a view of social justice that is invariably contradictory to the other views expressed. Theories of distributive justice to be discussed in Chapter 2 include:

- utilitarian;
- libertarian;
- communitarian; and
- egalitarian

The integration of the notion of justice into the project is significant as it gives an indication of how a particular Australian community feels about its health system and the values that it has towards the distribution of resources within this system.

In summary, the aims of this project are relatively straightforward but the methodology has required some careful development to enable the type of analysis necessary to address the key questions.
Chapter 2
Exploring Distributive Justice

2.1 Preamble

"The circumstances of the past year have been peculiarly unfavourable to the establishment of such an institution. The extraordinary increase in price of all articles required for outfit and consumption, the great expense of labour...have been causes of considerable difficulty." "Management has been impugned because applications have been refused when it was considered that the applicants were ineligible for admission as not coming within the objects of the Institution." (Subscribers to the Geelong Infirmary and Benevolent Asylum, 1853).

The problems experienced by the early pioneers of The Geelong Hospital in this 1853 quotation reflect the fundamental dilemma of health care provision. The allocation of resources to providers and the way in which these resources are then prioritised to specific service areas and patients remain the critical ethical decisions which determine the type of health system a community receives. Health care providers will never be given enough resources to satisfy all the demands placed upon them by a community that is becoming increasingly informed and demanding. Rationing of scarce resources is of course not restricted to the health sector as there are few areas of life where this is not a reality. Horvath (1990) considers that "it is the very success of health care and medical interventions that has rendered it necessary to make such decisions" (p. 437).

This chapter is concerned about the matter of justice as it relates to the distribution of health resources. There is a range of broader ethical issues that a society needs to consider if it wishes to have a just health system. In any endeavour to understand the values that a community has or to identify its priorities and expectations, a discussion about theories of distributive justice is informative. It assists in developing a framework for analysis and provides a useful means of distinguishing responses that emanate from the qualitative and quantitative research undertaken in this thesis.

The subject of justice is one that has attracted many authors and its discussion in this context involves the consideration of theories of distribution that may be applied to the
health sector. Four theories of distribution as they relate to health care are explored and consideration is given to the notion of what might be regarded as providing a "fair opportunity" for a community to access its health system. The theories explored are those adopted by Beauchamp and Childress (1994) who have studied the ethical dilemmas found in the medical area. The four theories of distributive justice that will be considered are:

- Utilitarianism — the greatest good for the greatest number.
- Libertarian — human wants will be satisfied by the market.
- Communitarianism — the application of community derived standards.
- Egalitarianism — equal distribution of social benefits and burdens.

The chapter translates the theoretical constructs of distribution into a practical situation that arose at The Geelong Hospital. The values that are used in decision making processes can be useful in understanding the sense of justice that prevails. By considering the Geelong example and applying several theories of distributive justice, alternative outcomes are achieved. This practical orientation is a useful tool for analysing how a community wishes to provide its health system. It is important to emphasise that the use of the example is not necessarily to provide the right answer but rather to assist in determining what ought to be the questions. If one thing is clear from the literature on this matter, it is that there is no decisive answer that determines that a particular situation is necessarily right or wrong.

This thesis is concerned with determining community priorities and expectations. Models of distributive justice assist in analysing community values. This is particularly useful in considering feedback from the qualitative and quantitative studies undertaken and reported on in Chapters 6 and 7.

2.2 An Ethical Dilemma in Resource Allocation

The Geelong Hospital is the second oldest hospital in Victoria and has a proud tradition of service to its local community. In an environment of economic rationalism, the hospital received budget cuts that accumulated to over 14%, in real terms, over the period 1994 to 1999. By necessity, the Hospital underwent substantial restructure with
workplace reform being a key feature. The Hospital’s capacity to absorb further cuts has diminished and it is regarded as a most effective and efficient performer.

The ethical dilemma for the Hospital is in determining how to deal with the increasing service demands being placed on the Hospital with fewer resources, yet retain the high standards of quality and service that the community and indeed the Hospital’s Board and staff expect. To illustrate this dilemma, a particular example is described. The example involves the implementation of cardiac surgery as a new service for The Geelong Hospital and the issues this creates for other services already being provided at the Hospital.

Planning commenced in the mid-1990s to develop a cardiac program at The Geelong Hospital for implementation in July 1997. Large amounts of money were invested in the construction of new facilities. Operating theatres were specifically designed for cardiac surgery and a new cardiac ward with a catheterisation laboratory and coronary care beds was built with a range of associated services. The total capital investment in these facilities and the associated equipment was in excess of $10 million (The Geelong Hospital, 1997). Costs of operating the new facilities vary according to the number of patients treated but with the minimum recommended number of 400 cardiac patients per year, the costs approximate $6 million.

The cardiac surgery initiative was strongly supported by the Victorian State Government of the day, The Geelong Hospital Board of Management and the community generally. Clinical staff in many areas and in particular the cardiologists, who have a direct interest in the service being developed, were obviously delighted, but there was less enthusiasm from some other members of the medical community. The advantages were clearly to provide better access to a tertiary level service in a more attractive geographical location and remove the need for patients needing this surgery to travel 80 kilometres to Melbourne. The social, clinical and political advantages of this were all very positive and difficult to challenge, at least in principle.

Those less enthusiastic queried why extra funds were allocated to cardiac care ahead of existing services that were in urgent need of additional resources because of the demands being placed upon them. Renal services, the neurosciences and orthopaedic
surgery were three areas that could reasonably have claimed this to be the case. Some health professionals in the area claimed a modest investment in health education and promotion activities would diminish the need for cardiac surgical interventions and therefore funds should have been allocated into that area.

The ethical dilemma is in deciding where additional resources should be allocated and on what basis. This requires a consideration of some key fundamental questions that Beauchamp and Childress (1994) described as:

1. What kind of health services will exist in a society?
2. Who will receive them and on what basis?
3. Who will deliver them?
4. How will burdens of financing them be distributed?
5. How will the power and control of those services be distributed?

These decisions are fundamental to the way a health system should be provided. However, the ability to influence these decisions is another matter because of the social and political framework that exists. The health care environment is subject to a range of influences with none as prominent as the political directions that are promulgated at various times. In considering the ethical and theoretical issues that surround resource allocation decisions, there is a constant need to bring the discussion back to the pragmatic of providing a service in this political environment.

The decision to commence cardiac surgery at The Geelong Hospital did not explore these questions in any explicit way. The reality was that the State Government provided additional funds specifically for the new services. The Government had positively responded to representations from the Hospital and medical community as the new services were consistent with its policy to provide services closer to where people lived. The services were also consistent with the emerging role of The Geelong Hospital as a tertiary referral hospital. The ability to substitute the funds made available to other areas of the Hospital’s service profile was not considered as it was the expansion into new services that was seen as the priority and indeed the only opportunity that existed to access additional resources. The failure to consider all the priorities and expectations of the Geelong community in reaching this decision supports the rationale for this thesis.
2.3 Justice and the Health System

In coming to terms with what sort of a health system should be provided, the notion that it should be fair, equitable and appropriate would be a popular proposition. The right to receive this care in light of what is due or owed to persons is an example of justice being practised. Indeed, when this is determined in accordance with justified norms that structure the terms of social cooperation, it is described as distributive justice. When there are issues of scarcity and competition, it is not so easy to establish the most appropriate distribution because there are competing demands that require judgements to be made and trade offs to be considered. (Beauchamp & Childress, 1994).

This issue of social cooperation is important because it enables society to provide a better life for all, than if individuals act totally independently of each other. The principles that are used to distinguish between the various social arrangements and to determine the proper distributive shares are the principles of social justice. The philosophical arguments provided by John Rawls (1973) provide an interesting context for considering matters of justice and fairness. He claims the principles of natural justice define the appropriate distribution of the benefits and burdens of social cooperation.

Distributive justice is an appropriate starting point for a consideration of what features could characterise a just health care system. Given the diverse nature and backgrounds of individuals, a broad community consensus on the most effective way of distributing justice would appear to be most unlikely. However, there is little evidence to validate such an assertion. There are a number of theories of justice that have been developed and each has a different perspective to offer and presents a view of social justice which is invariably contradictory to the other views expressed. A general description of each of these theories of justice follows; more to demonstrate their eclectic views than to reach a formal judgement.

2.3.1 Utilitarian theory of justice

Utilitarianism seeks to bring about good consequences to all concerned or as is most commonly described the “greatest good for the greatest number” (Preston, 1996, p.
The utilitarian theory of justice seeks to maximise public utility in the search for the greatest benefit to society. There are clearly potential losers with such a theory because marginal groups who have little to offer society but have a high propensity to consume health resources would be difficult groups to justify supporting. Leeder (1987) describes the worst aspects of utilitarianism result when professional judgements determine the social worth and liberty of the individual and cites the example of the foetus of a women from a lower socio-economic background which is aborted because it would be born into a disadvantaged environment. Society ignores the mother’s problems with the major concern being more about how the future of the yet to be born child will be a burden on the society. Under the utilitarianism approach, the greatest good for the greatest number will be achieved by pursuing an abortion. A policy of social justice which strives for fairness in the development of the mother as an individual with needs to be met, as well as fairness for the unborn foetus, would appear to be a more just system of care (Leeder, 1987).

How then does this theory of distribution contribute to the consideration of the dilemma of The Geelong Hospital? In deciding the benefits of cardiac surgery compared to the benefits of investing resources in other areas, this theory may have a role to play. A utilitarian approach has its attractions in that those who benefit from the preferred resource allocation will be, by definition, in the category of the “greatest good” and be able to assume the higher moral ground. It would be a reasonably simple task to decide on this by a quantification of the numbers of patients who could be treated under the various options. The utilitarian view would support allocating funds to where the greater number received care than necessarily the most deserving.

However, this would only give part of the story. It is the outcome of the treatment, which is most relevant, and some evaluation along the lines suggested by Maynard with his quality adjusted life years (QALY)\(^1\) may be more appropriate (The Ethics of Resource Allocation, 1990). Maynard suggests that a better form of resource allocation will be achieved by examining the costs and outcomes of competing therapies in terms of their relative effects on the quality of life for patients. Therapies that result in more

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\(^1\) The notion of QALYs has been supported strongly by Alan Maynard, Director of the Centre for Health Economics, University of York.
quality adjusted life years would be preferred to those that result in fewer. Despite the inadequacies in the techniques of estimating these outcomes, this approach has a utilitarian focus.

2.3.2 Libertarian theory of justice

In a literal sense, liberty is described as the freedom of the will (Flew, 1979). The libertarian theory of justice is treasured by the free marketeers who have great faith in the ability of the market to satisfy human wants. Any suggestion of an imposed equalisation process or social intervention is anathema to libertarians as it represents a threat to an individual’s liberty. An implicit characteristic of a health system based on this theory of distribution is the need to have health insurance or an ability to pay for services as required. A most striking example of a health system based on libertarian values is found in the United States of America (USA). The experience of this health system is that, notwithstanding their social service systems of Medicare and Medicaid, there remains in excess of 35 million people who have no capacity to pay for their health care.² The implications of this prompted a major review of the USA health system in the first term of the Clinton administration. Despite the recommendations that favoured a move to a more universally accessible system, the President failed in his bid for reform. The power of the libertarians throughout the nation proved too formidable.

The theory's ideology assumes patients are the best judges of their own welfare with priorities self determined and manifested through an ability to pay. Ability and needs of patients to access the health system are not necessarily congruent and the inevitable consequence is a distorted distribution of services. The inability of this theory to accommodate the needs of the disadvantaged by a mandated redistribution of society's assets makes this a difficult concept to embrace.

The libertarian theory would have both the cardiac service available at The Geelong Hospital as well as the other areas proposed so long as there was a demand for the services from paying or insured patients. Should there be insufficient numbers of payers then the services would not be provided regardless of the needs of the

² Figures vary but according to estimates from American colleagues, the correct figure is in this order.
community for these services. It is difficult to see this theory being embraced in a universal system of health insurance such as available in Australia.

-However, there are already divisions in the Australian community brought about by the availability of a dual system of health care in the public and private sectors with those able to afford health insurance having a speedier entry to health services. This accords with the libertarian view but the anomalies this creates are difficult to ignore. The waiting lists evident in the public sector for elective surgery are not to be seen in private hospitals. The ability to access this type of service quickly in the private sector is a function of the ability to pay but if this were to occur in the public system, would be contrary to the principles of Medicare that are the expected norms agreed between the Commonwealth and State Governments. Whilst libertarians would view this as justice, others more in need of the services might disagree.

2.3.3 Communitarian theory of justice

A community endorsed conception of social goals is how Beauchamp and Childress (1994) explain justice being achieved through the communitarian theory. This approach is based on community derived standards that seek to determine the ‘good’, the ‘right’ or the ‘virtuous’ in relation to particular traditions or social contexts (Preston, 1996, p. 206). This does not necessarily translate into having a health system that provides equal access for all at all times. If a community reaches a conclusion that places certain procedures as low priority, for whatever reason, then the person requiring that procedure may well be excluded from care. This may simply be exacerbating problems in another part of society.

In the State of Oregon, USA, a project was undertaken by the State Senate to set priorities in health care on a large scale. The method used involved adapting the notion of QALYs and soliciting public opinion. A conference was held in 1988 by a citizen’s health forum that advocated the allocation of health resources on a scale of public attitudes that quantified the trade off between length of life and quality of life (Citizens Health Care Parliament, as cited in Street & Richardson, 1992). As an outcome of the resultant study, a priority list of 709 items was produced which was then adapted to a given budget leaving 587 items to be covered from the basic package of health care available from the State (Street & Richardson, 1992). This is a striking example of
community based standards being applied to a most difficult area of society and indeed of communitarian theory.

The applicability of communitarian theory to the dilemma at The Geelong Hospital is fascinating because the same processes used by the State of Oregon could, theoretically, be adapted to Geelong. The geographical location of Geelong with a relatively well defined population makes it possible to ascertain community attitudes towards the relative priority of cardiac surgery compared to the other competing needs. The use of QALYs could assist in the process by evaluating the expected outcomes of one type of procedure compared to others. Whether the application of this theory of distributive justice would be embraced and accepted by the community is a matter of some intrigue and speculation.

A further concern in the implementation of this theory of distribution is to ensure the process is not taken over by the militant forms of communitarianism who support community control and reject liberal theories which they describe as “born of antagonism to all tradition” (Beauchamp & Childress, 1994, p. 80). The more moderate forms recognise the importance of various forms of community and recognise the autonomy and rights of individuals. This latter form is clearly more relevant in a discussion on health care in Australia because of the need to recognise the diverse nature of Australian society where liberal values need to be accepted as an intrinsic element.

2.3.4 Egalitarian theory of justice

The final theory of distributive justice to be considered is based on the concept of egalitarianism. This theory emphasises equal distribution of both social benefits and burdens. Rawls (1973) identifies two principles of justice for institutions. His first principle states: “Each person is to have an equal right to the most extensive total system of equal basic liberties compatible with a similar system of liberty for all.” His second principle states: “Social and economic inequalities are to be arranged so that they are both: (a) to the greatest benefit of the least advantaged...and (b) open to all under conditions of fair equality of opportunity” (Rawls, 1973, p. 302). Although it is not described as such, these principles offer a most persuasive description of egalitarianism as they articulate a notion of equality, fairness and opportunity. Daniels
has extended this interpretation further by describing a just health system as one where there is "fair equality of opportunity" where health consumers should be entitled to a fair share of the normal opportunities present and barriers should be reduced to enable this to occur (Daniels, 1985 as cited in Beauchamp & Childress, 1994, p. 340).

Rawls has inspired considerable support for egalitarianism because of the desirable political dimension to his proposal that all members of society are entitled to; as Beauchamp and Childress (1994) describe, a "decent minimum". This naturally leads into a discussion of what represents fair opportunity that is best summarised "as a rule of social distribution that attempts to diminish or eradicate unjust forms of distribution" (Beauchamp & Childress, 1994, p, 341).

The egalitarian theory is strongly supported because it identifies the non-discriminatory ideals of a just community. However, its application into the area of resource allocation is more problematic. The objective of seeking a fair opportunity to access health care implies an ability of the system to provide such a service and this will not always be possible. The issue of rationing becomes a feature of the system in such circumstances and this means that one area assumes a higher priority than another does. The egalitarian interpretation must take account of this and its integrity as a theory will be maintained only if all persons accessing the system are faced with the same range of alternatives. Rationing therefore needs to be effected in an egalitarian way so there is no discrimination within the area of service even though there may be discrimination between two competing services.

This distinction is important when considering the issue at The Geelong Hospital of providing cardiac surgery or expanding other services. The theory of egalitarianism can assist by considering the community’s ability to access a range of services and ensuring that all persons have access to a decent minimum range of services. The issue becomes one of defining the services required and ensuring all have a fair opportunity to access them.
2.4 The Issues of Resource Allocation

In allocating resources to highly technological and expensive procedures like cardiac surgery in an environment of severe cost constraints, it is reasonable to assume that health planners have adopted a policy of distribution, either explicitly or implicitly, that reflects one of the macro theories of distribution as described above. It is true that there is an inherent desire towards egalitarianism within the Australian health system with the fundamental basis of Medicare being equal access to public hospital services at no charge to the patient. Given the pressures on the health system brought about by a more demanding, better educated community and a minority number of people with health insurance, the ability of the public system to deliver an equal and fair opportunity for treatment is threatened. Certainly, those who can afford private care are advantaged in their ability to access private hospital services in a timely manner.

The Australian health system has been dominated in recent years with the desire to achieve technical efficiency that is concerned with the most efficient use of inputs and is reflected in such techniques as casemix\(^3\) or output methods of funding services. A just health system ought to be involved far more in achieving allocative efficiency which is aimed at maximising the effectiveness of resource allocations to achieve optimal societal outcomes. This is consistent with those who favour maximising utility but, if provided in a way where all people have equal access and opportunity, it may also satisfy the egalitarian advocates.

In medicine, the role of the broader good is often subordinated to the rights of individual patients and their immediate needs. This reflects the medical pre-disposition on theories of virtue and duty that are described as essentially individualistic ethics (McGuire, 1986). The natural tendency is, quite understandably, to deal with the short term issues of resource allocation rather than the more macro and longer term perspective. Whilst clinicians may have a view about the best methods of distribution, it is likely to be influenced by their own particular clinical background.

\(^3\) Casemix funding is a generic term used to describe a system of allocating resources on the basis of the cost of the particular case performed. Standard prices are adjusted by complexity and aim to fund service providers in a more homogeneous way.
In assessing the ethical dilemma of providing cardiac surgical services as a priority over other competing demands at The Geelong Hospital, an appreciation of the need for a just outcome is essential. The theories of distribution assist in developing a framework for considering the various options and the notion of providing an equal and fair opportunity for the community is based on sound social principles. The Australian health system tends to provide an over arching dictum best described as an egalitarian method of resource allocation. However, the other models could be adopted if community values decided that this was appropriate.

The utilitarian theory would require planners to consider the potential of recipients of cardiac interventions to contribute to society and this would form the basis of priority setting. These values would mean that fewer older patients would be treated with the emphasis on younger people who are able to contribute more to the “greater good”.

The libertarian approach would discriminate in favour of those who could afford to pay. Medicare does not permit this in Australia’s public hospital system but excessive waiting times and the opportunity for private care do create better access for those able to afford the associated costs in the private sector.

The communitarian theory necessitates a community view to priority setting that would rank cardiac surgery ahead of other competing needs.

This analysis assumes a level of objectivity from the community that may or may not be realistic. The more distant and dispassionate a person is from the dilemma then the more likely that person will be to make an objective decision. However, if the issue is personalised, either explicitly or implicitly, then it is likely that objectivity will be reduced. Herein lies the ultimate dilemma for decision makers in areas where rationing is required. Whereas a decision may be blindingly obvious for disinterested bystanders, the ability of those closely affected by the particular circumstance to make a reasonable decision may be extremely difficult. The design of any instruments to determine community views must take this into account.

Two other critical stakeholders in this analysis are the clinicians and the Government. As noted above, clinicians are likely to be influenced by their personal interests and the
interests of their patients. It is realistic to assume that the broader societal good would be a lesser priority in these circumstances. Government, on the other hand, has a responsibility to consider the macro issues and work with providers to achieve the most appropriate outcomes for society.

However, Government is also motivated by other competing priorities. The need to be providing new services is a reasonable goal for local politicians who wish to remain popular with their electorates and there are numerous examples where a pragmatic political decision has taken precedence over a sound health planning strategy.\(^4\) Government does have a major role in providing leadership on matters of resource allocation and should encourage debate at the macro level about this issue.

Strong community groups are likely to emerge in such debates and can potentially take over the process. The militant communitarians for example would have difficulty in accepting the benefits of a system that enabled individuals to exercise their individual rights (Citizens Health Care Parliament, as cited in Street & Richardson, 1992). However, the idea of gaining an understanding of community values and priorities is appealing. A more structured approach like the Oregon experiment would have a greater probability of successfully determining a community view that could become the basis for allocation decisions.

An alternate approach at a more local level is to utilise the hospital’s ethics committee to discuss the matter and to reach a position on how best to allocate resources. Ethics committees are constituted from a range of community and professional people who serve on a voluntary basis to give advice on ethical and research matters. They have been largely under utilised in addressing significant ethical issues and are a resource capable of being challenged more frequently.

Ultimately The Geelong Hospital will have to be accountable to its community about the way in which resources are allocated. This chapter has raised a series of questions and identified some opportunities for dealing with issues of resource allocation and the

\(^4\) The retention of acute public hospital services at the small rural town of Dunolly despite its close proximity to a major provincial centre at Bendigo is a good example. The building of the Essendon Hospital for overtly political reasons is another.
setting of priorities. The ethical issues are complex and, in a sense, have only been tantalisingly scratched through this analysis. The question of what a just health system looks like remains unanswered but by reviewing the theories of distribution that might be considered, a way to navigate through the labyrinth may be possible.

The next chapter considers how the application of the economic notion of scarcity is applied in the complex area of managing finite health resources in an environment of infinite demand.
Chapter 3

Scarcity in Health Care

3.1 Introduction

It seems trite to say that there will never be sufficient resources to satisfy all the wants in the health system but on the basis of the evidence available, that is exactly what would appear to be the reality. Successive Governments at both State and Commonwealth levels have, over the years, placed health as a major priority but rarely has this been translated into a major winner at polling day.

The matter being addressed in this chapter revolves around the notion that scarcity in health care is an inevitable outcome of an infinite demand for health care. The idea that demand will never be satisfied is anathema to the classical economic theory of markets that suggests that market equilibrium will be achieved when demand meets supply. If sufficient demand is identified, then the market will supply opportunities for this demand to be satisfied.

The health market does not offer the same characteristics of normal markets for a number of reasons. An inconclusive list would include:

- the inability for all to have perfect knowledge of the market;
- rational consumer behaviour does not prevail;
- price signals do not always deter or stimulate demand; and
- entry into the market is heavily regulated for potential providers of health services.

However, the most important reason for differentiating health care from normal market analyses is the role that the public sector plays in its management and operation. The financing of health care in Australia is a shared responsibility between the Commonwealth, State and Territory Governments and individuals, typically through co-payments to providers and health insurance premiums.

3.2 Health as a Public Good

In Australia, health care provision is essentially a “public good” in that it is provided under a publicly funded system of universal access. Although a minority of Australians
elect to have private health insurance, many of their health services are provided by the public sector. This is due to the limited range of health services provided by many private hospitals and the reliance on public hospitals for many tertiary or highly specialised services. Indeed, one of the strengths of the Australian health care system is that access is provided for all, regardless of capacity to pay or insurance status. Clinical need is the sole criterion that has any discriminating characteristic.

The high presence of the public sector in health care brings with it the need to adequately resource the system so that the objectives of access and quality care can be achieved. If the thesis at the beginning of this chapter holds true that there is an infinite demand for health care, then there will inevitably be a gap between what can be afforded and what is demanded. If this demand for health services cannot be met from normal market forces and the contention is that it cannot, then the public sector is unlikely to be able to produce the necessary funds to meet all the services that are demanded. Immediately this introduces the concept of scarcity which is a term adopted from the heart of economics. In economic terms, scarcity exists because wants are unlimited but resources are limited. All societies face the problem of scarcity and it is dealt with by making choices between alternatives with the preferred choice being the result of a rational, economic decision.

3.3 Making Choices about Health Services

Decisions about health, rather than economics, can be viewed from the perspective of both the broader community and the individual. The utilitarian approach discussed in Chapter 2 is a good example of how this point can be illustrated. The "greatest good for the greatest all" is a principle that can be readily argued in the abstract because it has the intuitive sense that people in a democratic society can relate to comfortably. However, the case of an eight year old leukemia sufferer who is denied bone marrow transplantation because the chances of prolonging life to any significant extent are very poor, will attract front page media coverage and places the Government of the day in an invidious position.¹

¹ The Oregon Health Plan is discussed in more detail in Chapter 2
This is the situation that the legislature of Oregon, USA found itself and was the catalyst for what became the most radical attempt to prioritise health care in recent history. In an address in Australia, the Governor of the State of Oregon, John Kitzhaber (1999) commented that the objective of the health system is to produce health and if it is not achieved then the intervention being considered needs to be questioned. Health care is a means to achieving health and the challenge is to align the cost of the system to the health that is produced. Even if the Government had sufficient funds to perform the procedure on the child, and Kitzhaber states that they did, to allocate funds for this purpose ahead of a range of other priorities was not justified. In this particular case, the health of the patient was not being improved so the treatment did not proceed. The portrayal of the Government as being uncaring is understandable but its actions would seem to be a reasonable application of utilitarian theory in resource distribution.

Economic or cost considerations provide another dynamic that cannot be ignored in this analysis. The Oregon example, while justified on clinical grounds, is also capable of support from an economic perspective. The allocation of funds on the basis of emotion rather than clinical and economic criteria may be pragmatically attractive to Governments seeking electoral support but indicates a poor response to complex public policy questions. The ultimate corollary is for every controversial matter to be dealt with in the same way with public policy being built up on a case by case basis.

3.4 The Rationing Dilemma

In health systems, if there is not enough resource to do everything, then there will be times when something will not be able to be done for someone. This is the ultimate test of how communities deal with the issue of scarcity or, as is perhaps better described, the rationing dilemma. One way of dealing with it is to state the priorities in an explicit form such has been undertaken in the Oregon example discussed here. Other countries, such as New Zealand, The Netherlands and Sweden, have also followed this lead but with varying degrees of success. In an interesting analysis of international perspectives, Maxwell (1995) has edited a more complete summary of the experience of these countries although time has now superseded some of this historical context.
In his excellent book on rationing health care, David Hunter (1997), the Professor of Health Policy and Management at the Nuffield Institute for Health (UK) describes a range of approaches to implicit and explicit rationing and uses international examples as illustrations. Hunter is clearly an advocate for implicit rationing, not from any position of favouring a paternalistic approach by medical practitioners or being dismissive of consumerism, but rather from a position of pragmatism and what he calls the realpolitik of health care decision making. In summary, this suggests that the decisions faced by political leaders, practitioners and managers are of such complexity that any attempt to explicitly and objectively determine priorities is doomed to failure or be so vague as to be meaningless. A realistic rather than idealistic view is what Hunter believes is appropriate.

It is from this position that Hunter argues the case to “muddle through elegantly” and advocates a more subtle and incremental approach to dealing with rationing dilemmas. Clinicians that are informed by community views including those of their patients are likely to make better decisions. The development of national guidelines on priority setting establish a policy framework for this to occur. An explicit listing of health priorities is neither feasible nor possible for the community to contemplate and “muddling through elegantly” enables change to occur in how decisions about priorities are made but at a more micro level and within current arrangements (Hunter, 1997).

It is an interesting phenomenon that the notion of priority setting is regarded as an appropriate means of making decisions but the suggestion that services are to be rationed is often regarded with contempt. However, the direct corollary of acknowledging that scarcity exists is that rationing must occur. This contempt may be due to the historical use of the word rationing and in particular the use of rationing during periods of particular hardship such as war or depression. In the context of the present discussion, the words rationing, priority setting and scarcity all have similar implications.

3.5 Reactions to Rationing

Social policy analysts Klein, Day and Redmayne (1998) have described health care rationing as being little different to all publicly funded services where there are
constrained budgets and unconstrained demands for resources. In more economic terms, supply is constrained by considerations of cost but demand is not restrained by considerations of price. The practical manifestation of this occurs when decisions are taken that limit, or ration, services. When the patient or their families expose the decision to wider public scrutiny, a predictable response occurs.

A famous example of this in the United Kingdom was the case of Child B, later known as Jaymee Bowen (New, 1996). In this case, a ten year old girl with leukaemia was denied further treatment because her prognosis was poor and the pain of the treatment was not seen as being a reasonable thing for her to endure. This view was widely supported by clinicians specialised in this field. The patient's father took the Cambridge and Huntingdon Health Authority to court and finally, the High Court of Appeal decided in favour of the health service. The public furore over this decision placed great stress on the Health Authority and its management with the vast majority of responses being negative against the Authority. The populist view was that the National Health Service (NHS) should provide the funds to undertake the further treatment regardless of the likely outcome. The notion that everything that can be done should be done reigned supreme.

The decision of the High Court of Appeal was an important watershed for the NHS and those who seek a rational approach to these types of decisions. The irony is that the associated negative publicity also acts as a powerful dis-incentive for others wishing to proceed down a similar path. In such cases, the public perception is that demand must be met regardless of price and no rational, clinically based argument is likely to change that opinion. The image received by the public is of a young girl denied access to available services and this is where the argument ends. The idea of scarcity of resources becomes irrelevant in these circumstances and the Hunter (1997) idea of "elegantly muddling through", an attractive option.

### 3.6 Managing Scarcity

In conclusion, managing scarcity in health care is a challenge for all those involved in resource management, either at a macro or micro level. Difficulties arise in the translation of theory into practice because whenever this occurs, there will be a real
person with real problems who is affected by the decision taken. The potential repercussions of the decision in practical political terms can be dramatic and frequently results in the application of a pragmatic solution. Such is the realpolitik of health care.

However, a more informed community that has the opportunity to articulate a view about the priorities that should be adopted by a caring society, may improve the debate. It is for this reason that attempts need to be made to determine the views of communities in a more systematic way. While the sympathetic reaction to a child with cancer may never be changed, and perhaps it never should, a community that can express a view about such matters in a less emotive environment may assist those in positions of power when decisions need to be taken.

The next chapter explores the possibilities of the community having a major input into health care decision making processes including resource allocation by examining a range of opportunities that enable communities to participate. It develops the notion of meaningful community involvement in considering the dilemmas that have already been identified in this chapter and in addressing the key research questions of this thesis.
Chapter 4
Community Participation in Health Care

4.1 Introduction
One could be forgiven for thinking that community participation was a new phenomenon given the public revival it has experienced in more recent times. The State Government of Victoria has explicitly expressed its commitment to community participation in its policy documentation (Australian Labor Party, Victorian Branch, 1999) and has implemented the policy in several spheres of its operations. The creation of community advisory committees in the health system is but one example of this policy being actioned.

The truth is that community participation has been a feature of multiple systems for a very long time. What seems to have changed is the recognition formally of the need to move from community involvement via consultation processes to a genuine attempt to meaningful participation in decision making processes. This chapter considers some of these changes, particularly as they relate to the health care system.

4.2 Some Early Experiences of Community Participation
Community participation in decision making about health care services in the United States is reported to date back to a Cincinatti experience in 1917 (Anderson & Kerr, 1971). The Victorian system of managing health care organisations in the public arena, notably public hospitals and community health centres, has an even longer tradition of community involvement.¹ Public hospitals were commonly the result of a groundswell of community action with facilities being developed, often by public subscription and philanthropy and modest Government support. Needs were identified and communities galvanised to achieving their objective of access to local health services. Even now, numerous communities throughout Victoria jealously protect their right to have their local hospital maintained in order to protect this objective.

¹ The first public hospital in Victoria, the Melbourne Hospital, was formed with its own Board of Management in 1848.
However, the context of local health care has changed dramatically. Improved transportation, development of specialised medicine and a concentration of resources in larger centres have diminished the role of the small, local hospital. Concurrent with this, the role of community participation has also changed.

The role of Government has also grown significantly with funding of public hospital services being almost entirely the responsibility of either Commonwealth or State Governments. Barwon Health for example now has 78% of its income coming directly from the State Government, 8% from the Commonwealth Government and only 6% from patient fees. The remainder comes from miscellaneous sources including business units (Barwon Health, 2000). Health insurance funds contribute the bulk of the patient fees as a consequence of the insurance held by patients.

The “contributors” elected the Boards of Management (called Committees in those days) that operated the early public hospitals. Any adult person who paid the prescribed fee could become a contributor and was eligible to vote at the hospital’s annual meeting. It was here that the Board was elected from those in the community willing to put themselves forward. This representation, that dates back to 1848 with the formation of Victoria’s earliest hospital, the Melbourne Hospital, continued in essentially the same form until the State Government decided to directly appoint public hospital boards in 1982.

This was community participation in its purest form with the Boards being totally responsible for the operations, fund raising and organisation of the hospital. The community elected board members were directly accountable to their community with the ultimate sanction being their non-election at the next ballot. As Governments have increasingly assumed the role of funding hospitals, so the autonomy of the local Board has diminished. Rigorous instructions and guidelines across a multitude of areas are now in place to ensure Governments protect their assets. This of course is all in the quest for accountability of hospital boards, not only to Governments but also to their community.

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2 The Geelong Hospital was Victoria’s second public hospital being formed in 1852.
4.3 Community Health Services as a Model of Community Participation

The discussion to date has centred on public hospitals but a further change that has occurred over the past thirty years has been the increase in community based services. Community health centres were a vehicle for active community participation and it is useful to briefly look at their origins. The community health movement gained its momentum from the initiatives of the reformist Commonwealth Labor Government that swept to office in 1972 under the leadership of Gough Whitlam. The work of the Hospitals and Health Services Commission under the leadership of Dr Sidney Sax\(^3\) set the agenda for the community health sector that remains to this day. The idea behind community health centres was to provide a wide range of ambulatory services in non-institutionalised community locations. In addition to maintaining the medical aspects of health care, the notions of health education, health promotion and health prevention were actively pursued.

In much the same way public hospitals had community elected boards, community health centres were also managed by their own community boards. However, the community ownership and management principles that underpinned these reforms were eroded with another reformist Government, this time at the State level in Victoria under the leadership of Jeff Kennett who was Premier of Victoria between 1992 and 1999.

Consistent with the philosophy of professional boards in all parts of the public sector and fiscal accountability, this Government introduced Government appointed boards to community health centres. The idea of community participation at Board level was not a priority at this time. Since the return of a State Labor Government in 1999, this has changed again with legislation introduced in late 2000 enabling approximately half of each community health centre board of management to be community elected with the remainder appointed by Government.

4.4 Community Participation in Contemporary Health Services

The maturing of the health service system has seen a number of new organisations evolve that embrace the idea of integrated and co-ordinated care. Public hospitals,

\(^3\) Sax S. Chairman of the Hospitals and Health Services Commission, 1974.
rehabilitation facilities, aged care facilities and in some cases, community health centres have merged to form new organisations. In Melbourne, these organisations are called Metropolitan Health Services. The Minister for Health appoints all the Boards of Directors in these Metropolitan Health Services but at least one member of each Board must be able to demonstrate a consumer perspective.

This is one way of the State Government actively promoting the concept of community participation in Victoria’s health services but a more meaningful way is demonstrated by its release of non-statutory guidelines for Metropolitan Health Services to use in the creation of community advisory committees (Victorian Government Department of Human Services, 2000). Each Metropolitan Health Service is required to create a community advisory committee and sample terms of reference as quoted below encapsulate the Government’s expectations.

"The community advisory committee will:

- Advise the Health Service Board on strategies to enhance and promote consumer and community participation at all levels within the Health Service, including the development of a strategic Community Participation Plan;
- Identify and advise the Health Service Board on priority areas and issues requiring consumer and community participation;
- Monitor the implementation and effectiveness of the Community Participation Plan;
- Assist the Health Service Board and the Executive in their communication with the Health Service’s community and consumers;
- Advise the Board on major strategic issues and initiatives;
- Generally advocate on behalf of the community to the Board;
- Participate in the Health Service’s broad strategic planning and service development processes;
- Assist the Health Service Board in the development and ongoing monitoring of key performance indicators for service quality and accessibility;
- Undertake other activities and projects as agreed with the Health Service Board from time to time" (Victorian Government Department of Human Services, 2000, p. 6).
The importance of this more formalised approach to community participation should not be under-estimated, as it is clear that the Government expects meaningful participation to occur. Boards of Directors are required to annually report on the activities of its Community Advisory Committee and the actions taken by the Board in relation to the recommendations made to it by the Community Advisory Committee. The Board is also expected to regularly report to the community on the activities of the Community Advisory Committee through its newsletter, web site, public forums or other means (Victorian Government Department of Human Services, 2000).

Interest in community participation has been stimulated in Victoria by the policy platform of its State Government. This is not only about ensuring Boards of Directors are appointed with a greater community focus, although each new Board of Metropolitan Health Services has at least one person capable of giving a consumer perspective, but it is also about changing the way that health services make decisions.

Traditional power bases of large public hospitals, regardless of the governance role of Boards of Management/Directors, have resided in the hands of highly influential members of the clinical staff. These are the people who until 1975 worked as Honorary Medical Staff. Health professionals who worked in that period describe many of the medical staff as paternalistic and largely benevolent in manner. The advent of remuneration, more highly skilled management and greater accountabilities has already changed this traditional power base. Nevertheless, the role of consumers and the community in determining strategic directions has not been, typically, well supported. The opportunity to have the community more actively engaged is one that has been welcomed by many and not so welcomed by others. It provides a challenging scenario for Boards, managers and clinicians alike but the way forward has been clearly articulated by the Government of Victoria and is being implemented throughout 2001.

The Victorian Government created a Ministerial Review of Health Care Networks to advise it on a range of matters including mechanisms to ensure consumer involvement. The report of this review panel (Duckett, Capp, Carter, Lowe, & Zimet, 2000) sets out a rationale for community participation and this has formed the basis for the decisions

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4 Based on the personal observations of the author.
subsequently taken by the State Government. Importantly, the review panel recommended and the State Government accepted that community advisory committees and board representation were only two of a large range of options that health services should adopt (Duckett et al., 2000). However, the recommendation on community advisory committees did represent a formal response to the issue of community participation.

4.5 Methods of Community Participation

Seeking the views of the community in health care is viewed by many as a given that needs no debate. This may be the case, but determining the best way of involving the community can be challenging. There is a range of examples reported in the literature about different methods of community participation. In 1992, the UK Department of Health encouraged health authorities to consult with their communities in matters of purchasing and priority setting. Angela Coulter (1999), the Executive Director of Kings Fund, London provides a concise summary of the initiatives tried in the years that followed. These techniques for consulting the public are:

- Surveys and opinion polls;
- Rapid appraisal;
- Public meetings;
- Focus groups;
- Standing panels;
- Citizens’ juries;
- Deliberative polls; and
- Future search conferences.

4.5.1 Surveys and opinion polls

Perhaps the most published of the UK researchers in the area of population-based surveys and opinion polls is Ann Bowling (1996). Her work was the first attempt at prioritising lists of treatments and services based on a random sample of the national population. The 75% response rate resulted in a sample size of 2005. In terms of community participation this was a major exercise that produced some very interesting results. Not only was a ranking of health services determined but there was overwhelming endorsement of the technique as a useful source of obtaining the
community view in how health services should be planned. The outcomes of this particular survey will be referred to again when reflecting upon the major survey conducted as part of this thesis.

4.5.2 Rapid appraisal
Rapid appraisal is a method of involving representatives of groups in the community who can then participate in a discussion about relevant topics. It is a convenient and time efficient way of engaging a broad range of stakeholder groups but the success of the process revolves around how truly the nominees actually represent their group. As Bowling (1996) observes, rapid appraisal techniques can be useful at a neighbourhood level but cannot be a substitute for the need for representative information that deals with specific questions. As the size and system of recruitment will be determinants of the success of this process, it is a method of informing rather than an opportunity of generalising to the broader population.

4.5.3 Public meetings
Public meetings are a frequent means of interacting with a community but it is difficult to conclude that they represent the community view. Unless there is a major issue about which there has been widespread publicity, public meetings can be poorly attended. General invitations to discuss the future directions of health care in Geelong failed dismally because there was no major community issue to focus upon. Three public meetings were held by the fledgling organisation, Barwon Health, to elicit the views of the community about the strategic directions that the health service should follow. In short, the meetings were attended by more of the Board of Directors and senior management than members of the community.

A useful example of the concept of public meetings is sourced from Oregon (Bowling, 1992) where members of the community were asked to contribute to the discussion about the value system that the public use in reaching decisions about the health system. A total of 1,048 people attended one of the 47 meetings held throughout Oregon.

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5 Personal observations of the author who, at the time, was Chief Executive of Barwon Health.
The work in Oregon was about determining priorities for that section of the community receiving Medicaid but only 4.4% of those attending the public meetings were in that category. A further 9.4% were uninsured with the remainder being college educated, Caucasian, in higher income brackets, medical students and health professionals (Bowling, 1992). The danger of drawing too heavily upon public meetings is that they can be unrepresentative of the target population and this was certainly the case in Oregon. A further complication is that meetings can be dominated by a vocal minority and unless there is a systematic way of determining opinion, many people attending a public meeting may never feel able to have their say.

4.5.4 Focus groups
Focus groups have long been an accepted means of testing opinion in the marketing area and are now regarded highly in the field of behavioural research. This qualitative research technique explores a pre-defined topic in an open and flexible way. It allows skilled facilitators to gain the confidence of participants and draw out their opinions, feelings, attitudes and behaviours (Murphy, Cockburn, & Murphy, 1992). Focus groups have the advantage of being time efficient and are able to canvass a range of views from different perspectives. They enable interaction between the participants in a way not possible through quantitative methods.

4.5.5 Standing panels
Standing panels are capable of being formed at any time to consider specific issues. One UK experience at the Somerset Health Authority was to form eight panels to consider matters of resource allocation. Each panel was appointed with a view to achieving a balance of age, sex and socio-economic groupings. After giving information about the issue and discussion among panel members, a decision was sought (Coulter, 1999).

4.5.6 Citizens’ juries
The more vigorous extension of the standing panel is the citizen’s jury, a further mechanism to involve the community in health decisions. This was first trialed in the UK at the Cambridge and Huntingdon Health Authority. The jury of sixteen was picked by stratified random sampling so it could be representative of the community. It sat for four days and heard from expert witnesses about the options for setting priorities in the
NHS at the national and more local level. The jury advocated a national council for priority setting with some lay involvement on the council. More importantly, the process was seen to be a most effective means of community participation and confirmed that time and information were important to the jury being willing and able to contribute to the debate about priority setting in health care (Lenaghan, New, & Mitchell, 1996). There remain questions about how well citizens' juries represent the community and the relative cost of undertaking the process is also a concern to those charged with encouraging community participation.

4.5.7 Other techniques
Deliberative polls and future search conferences are also expensive to establish and again the method of recruitment can be problematic if a representative group is to be convened.

Of all the options available for community participation, the objectives of this thesis are considered to be best met by adopting a focus group approach for part one of the research. A key feature of well conducted focus groups is drawing out the views of participants and allowing free and frank discussions (Morgan, 1988). This is the outcome being sought and as the selection processes adopted ensure that there is a wide range of views being invited, maximum benefit is derived.

Similarly, community based surveys that are appropriately recruited with a well constructed interview schedule seem to be the most rigorous approach to determining community views (Quine, 1985). Other options are either too expensive to conduct or likely to have significant shortcomings in their interpretation. The rationale for the second part of this research to be a community survey is based primarily on having confidence in the outcome.

This chapter has given both an historical and contemporary context to community participation. It has shown how community participation is being adopted as a concept in the State of Victoria and provides a context for the work being carried out in this study. It has also identified a range of opportunities that exist for the community to be involved in the decision making processes in the health system.
In summary, the preferred model to be developed in this thesis harvests the extensive benefits of focus groups in the eliciting of key themes. The information obtained from this qualitative research is then used to inform the development of an interview schedule that can be used in the quantitative survey of the Geelong community.
Chapter 5

Community Participation in Geelong

In Chapter 1, some of the background was outlined as to the reasons why this study occurred in Geelong and the close association between the research and the planning processes of Barwon Health. This chapter expands upon the previous comments and considers why this type of work is regarded as important by Barwon Health. It then considers the preferred models for community participation.

5.1 The Setting of the Study – Barwon Health

Barwon Health is an organisation formed in 1998 as the result of a voluntary amalgamation of five health care organisations. These included:

- The Geelong Hospital, a 400 bed teaching hospital of both the University of Melbourne and Deakin University;
- Grace McKellar Centre, a 445 bed rehabilitation and aged care facility; and
- Surf Coast, Corio and Geelong Community Health Services providing a broad range of ambulatory services including dental and mental health.

The voluntary nature of the amalgamation is significant because it reflected a shared vision about the way that health services will be delivered in the future. This vision incorporates integrated and co-ordinated systems of care that do not rely upon the “silo” or institutional based models of care that have traditionally prevailed in the Victorian health system.

A further dynamic that has evolved is the commitment to engage the community in a meaningful way in the planning of future health services. This was explicitly manifested in the Barwon Health strategic plan with a key objective being the identification of the priorities and expectations that the Geelong community has of its public health care system (Barwon Health, 1998). The mechanism for achieving this objective is the development of this thesis. The outcomes of the thesis will inform the Board of Directors of Barwon Health to assist in its future planning.

The objective within the strategic plan was a clear recognition that Barwon Health viewed community participation as an important dynamic in its decision making
processes. It was also a response to other concerns that were being expressed about expectations and the demands being placed on services that were under financial pressure. The drivers for this thesis being an important part of the work of Barwon Health are summarised as follows:

- a commitment to community participation;
- clinician concerns about community expectations; and
- the inevitability of rationing health services.

5.2 A Commitment to Community Participation

From its early beginnings, Barwon Health’s Board of Directors and senior management team acknowledged that an accessible, high quality and cost effective health service needed community involvement if it was to deliver responsive and appropriate services. The convening of a number of public forums to acquaint the community about the organisation and seeking its views about future directions evidenced this. The formalisation of this view in the Barwon Health strategic plan was an explicit statement of commitment and has resulted in this thesis being developed.

The community has a strong affinity with the major health services in Geelong. The catchment population of health services is always a little problematic because of the way that services in major regional centres are provided. For example, The Geelong Hospital provides cardiac and cancer services to all of Western Victoria but the local community is usually defined as the Barwon sub-region. This sub-region is an area that encompasses the local government areas of the City of Greater Geelong, Surf Coast Shire and part of the Golden Plains Shire. Conservatively, the Barwon Health catchment is approximately 230,000 persons. In the course of a year, many people have contact with one of the Barwon Health services.

In the 1999/2000 financial year (Barwon Health, 2000), about 45,000 inpatients were cared for and persons attending the emergency department at The Geelong Hospital totalled over 37,000. Other community contacts exceeded 100,000. Even allowing for multiple attendances by individuals, the penetration into the community from Barwon Health is very significant.
A daily newspaper, The Geelong Advertiser, is published in Geelong and this is a further reason for the community to be close to the activities of Barwon Health. For better or for worse, the Geelong Advertiser publicises extensively the positive and not so positive stories about the health service as it sees Barwon Health as a major player in the area. This is quite justified, as Barwon Health is the largest employer in the region with 3,300 employees and a major source of economic activity with an annual turnover approaching $200 million (Barwon Health, 2000).

The Board of Directors and management team are strongly connected within the community through the range of contacts and networks that each person possesses. However, they cannot conceivably be aware of all views. Most Board members are in their respective positions because of a particular skill base that they bring to the Board. These may be a legal, financial, clinical or consumer perspective. A strong management focus brings with it awareness that key stakeholders need to be engaged in planning processes if they are to have any ownership of the outcomes. This view has assisted in developing the strategy for community participation at Barwon Health.

The policy of the Victorian Government is to support community participation at all levels and as has been discussed earlier, has implemented the policy by requiring Melbourne’s health services to establish community advisory committees. It is perhaps notable that Barwon Health embarked on its community participation projects prior to the State Government initiatives in this area and this has resulted in a quite mature approach being in place compared to some other health services in Victoria.

5.3 Clinician Concerns about Community Expectations
There are increasing concerns from clinicians that community expectations are placing unrealistic pressures on the health system, particularly in critical care areas when the prognosis of the patient is poor. These concerns are emerging in the context of increasingly stringent financial budgets as a result of several years of resource constraints.¹ This has lead to clinician managers questioning far more closely the areas of expenditure within their span of responsibility and indeed other instances of high resource utilisation within the health system.

¹ Public hospitals in Victoria have been subject to budget cuts of at least 1.5% annually since 1992.
These concerns are best illustrated with an example that occurred in the intensive care ward at The Geelong Hospital. The elderly mother of a leading citizen of the Geelong community was admitted to hospital as a consequence of her deteriorating medical condition. It was clear to all treating clinicians that this woman’s life was coming to an end, as her particular condition was unlikely to respond to treatment. When confronted with this scenario, the consultant physician spoke with the family who pushed hard on the idea that if there was any chance of recovery, regardless how small, then every possible step should be taken. The consultant accepted this view and sought the patient’s admission to the intensive care unit to actively pursue treatment. This was done in the knowledge that the outcome was likely to be poor but was a response to the expectations and demands of the family.

The Director of Intensive Care was appalled at this request as he was placed in a most difficult position. If he refused the request he was in open conflict with a senior colleague and the patient’s family but if he cared for the patient he was exposing his unit to costs and clinical care that he knew would not improve the prognosis of the patient. Notwithstanding the consequences, the Director spoke with the family and expressed his concerns whereupon he was accused of being “heartless and uncaring”. The patient was admitted to the intensive care unit and was actively treated for several days until it became apparent to all, including the family, that there was not going to be a miraculous recovery. The patient died after two weeks in the intensive care unit, the costs attributed to her care exceeded $80,000 and the Director of the unit felt enormously frustrated.

Similar examples can be related by clinicians in other areas of care and it seems that the availability of the technology and clinical expertise has developed an expectation that miracles can happen. Ironically, there are some occasions when miracles can be said to have occurred. These are invariably presented in the media as outstanding progress of medical science and there is much to be said in favour of this view. However, does one success justify the huge costs of the many failures? This is the question that gets to the

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2 Personal observations of the author who was, at the time, Chief Executive of Barwon Health.
heart of evidence based clinical practice and is one of the greatest sources of conjecture for those involved in clinical care.

5.4 The Inevitability of Rationing Health Services

There would be fewer concerns about the dilemma faced by the Director of Intensive Care and his colleagues in a health system that had limitless funds. Clearly, in such a system, everything that can technically be done should be done and the absence of a cost imperative would most likely change behaviour. Chapter 3 discussed the notion of scarcity in health care and has canvassed the likelihood of such a situation. Even if it were to occur, it would be a most unusual phenomenon.

At some stage, rationing or prioritisation of health services will become a major issue in Australia. This will be the inevitable consequence of demand exceeding the supply of health services that the community is prepared to finance. Demand will increase as the ageing population becomes a greater proportion of the total population. The greatest users of the health system are those aged over 65 years of age and this group is predicted to increase significantly over the next 20 years. It will also grow because of the availability of new technologies that have been and will continue to develop. The final reason it will grow is because public expectations will demand that the technologies that are available will be used.

In an environment of expanding demands and limited sources of funding, developing systems of priority setting will become the challenge for community leaders and health planners. In order to have a sensible debate about how this might work, community values and expectations need to be understood. Chapter 2 has referred to the models of distributive justice that can be useful in gaining this understanding.

The drivers that have influenced Barwon Health to be interested in developing community participation appear to be useful to similar health services in Australia and overseas. The distinguishing characteristic of Barwon Health is that the Board of Directors and management team has been prepared to address the issue and support the work inherent in this thesis in order to involve the community in articulating its view about some of these matters.
5.5 Preferred Models for Community Participation

Chapter 4 has detailed several models for community participation. It is clear from this analysis that these models are not mutually exclusive and it seems desirable to use several different approaches depending upon the issue being addressed. From a Barwon Health perspective, a community advisory committee is being developed and this will enable a number of models of community participation to be developed. For example, the community advisory committee could, in its own right, establish a number of task groups to explore specific matters to better inform itself about community views. It could, either independently or in conjunction with the Board of Directors, hold its own community forums, have a search conference or conduct focus groups. A further option available to Barwon Health is to undertake a community survey.

This thesis describes a process and its outcomes, which are designed to effectively seek out a representative view about community priorities and expectations through a quantitative survey of the Geelong community. It is useful at this stage to restate the research questions. The study set out to:

1. Identify the priorities and expectations that the Geelong community has of its public health care system.

2. Determine if there is a common view on the attributes of a just health system.

3. Consider a method of utilising the data in the determination of health care priority setting in Barwon Health.

4. Determine a model of community consultation which enables ongoing input into the decision making processes of Barwon Health.

To ensure the themes of the survey are consistent with the likely interests of the community, a series of focus groups was formed. The work that will be reported upon in Chapters 6 and 7 is the product of a two part research study. Chapter 6 reports upon the first part of the research, which was a focus group study. The outcomes of this
qualitative work assisted in developing the interview schedule for the quantitative study that is reported upon in Chapter 7. This second part of the research sought responses from 400 members of the Geelong community through a series of telephone interviews.
Chapter 6
Community Participation Through Focus Groups

6.1 Introduction
This chapter presents the qualitative research that forms the first part of this two stage research study. It does this by reporting on research based on a community participation model of data collection using focus groups as the technique. In order to understand more precisely the way that the focus groups were conducted, the remainder of this chapter considers the sample and methodology used, including the participants, the procedures taken, the questions asked and the data analysis. The major part of the chapter presents the results.

The use of focus groups as a means of generating data has assumed a high level of popularity in health research in recent years. Kitzinger (1995) advises that focus groups are being used extensively in assessing health education messages and examining public understandings of illness and of health behaviours. Morgan (1988) has noted the particular benefits that focus groups present in exploratory research such as in the identification of trends and insights in beliefs, opinions, misconceptions and behaviours. Focus groups are seen to be particularly useful in generating hypotheses and developing questionnaires.

The principal purpose for this study of engaging in qualitative research is to develop questionnaire items. The eliciting of views on a range of matters, including some that are controversial, gives insights into the values and beliefs held by participants. This in itself creates a good deal of research material. However, it also helps inform the second part of this research study by highlighting areas for more focussed interrogation in the interview schedule developed for the community survey.

6.2 The Sample and Methodology
6.2.1 Ethical approval
The Research and Ethics Advisory Committee (REAC) of Barwon Health approved this part of the research study (refer Appendix A). This committee is constituted and operates in accordance with the National Health and Medical Research Council’s
National Statement on Ethical Conduct in Research involving Humans (1999). Full approval was granted on 30 December 1999 under Study 99/71. Participants who requested a summary were mailed a summary of the findings of this study on 6 June 2000 (refer Appendix B). A Final Report was submitted to the Research and Ethics Advisory Committee of Barwon Health on 23 November 2000.

6.2.2 The participants
Eight focus groups were conducted with members of the Geelong community. Each group comprised individuals with similar demographic characteristics. Four of the groups were conducted with men, and four with women. Three groups were recruited from lower socioeconomic status (SES) areas of Geelong, and three from higher SES areas of Geelong. Three groups comprised individuals aged over 40 years (referred to as "older"), and three groups comprised individuals under 40 years and under (referred to as "younger"). Two groups comprised people from an Italian background. The number of participants in each group, and the composition of the eight groups are presented in Table 6.1.

Table 6.1 Composition of the Focus Groups

<table>
<thead>
<tr>
<th>Group and Composition</th>
<th>Group and Composition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group A</td>
<td>Group E</td>
</tr>
<tr>
<td>Men, older, upper SES</td>
<td>Women, older, upper SES</td>
</tr>
<tr>
<td>( n = 8 )</td>
<td>( n = 6 )</td>
</tr>
<tr>
<td>Group B</td>
<td>Group F</td>
</tr>
<tr>
<td>Men, younger, upper SES</td>
<td>Women, older, lower SES</td>
</tr>
<tr>
<td>( n = 7 )</td>
<td>( n = 8 )</td>
</tr>
<tr>
<td>Group C</td>
<td>Group G</td>
</tr>
<tr>
<td>Men, younger, lower SES</td>
<td>Women, younger, lower SES</td>
</tr>
<tr>
<td>( n = 11 )</td>
<td>( n = 5 )</td>
</tr>
<tr>
<td>Group D</td>
<td>Group H</td>
</tr>
<tr>
<td>Italian men</td>
<td>Italian women</td>
</tr>
<tr>
<td>( n = 11 )</td>
<td>( n = 8 )</td>
</tr>
</tbody>
</table>

Several recruitment methods were utilised in this study. All participants were members of the Geelong community with no expert knowledge of health issues. The participants were recruited from letters mailed to service clubs, the researcher attending playschool
groups and a relaxation class held at community centres and inviting individuals to participate, via a Salvation Army outreach worker and St Laurence Community Services Day Program co-ordinator, from leaflets distributed at Barwon Health's community health service at Corio, and via the President of the Geelong Italian Social Club. A small number of individuals who responded to an article in the local newspaper, The Geelong Advertiser, and who did not have any expert knowledge of health issues also participated. When other recruitment methods failed to produce sufficient younger males from the upper socioeconomic areas, some individuals were approached by two colleagues of the researcher and invited to participate.

A total of 64 individuals participated in a focus group. Table 6.2 (next page) shows the demographic characteristics of the sample. The larger number of males occurred mainly due to larger numbers of men being recruited to the Italian men's group, and to the younger, lower SES men's group. The people assisting with recruitment for these groups invited more participants than necessary as it was anticipated that several would not attend. However, all invited individuals attended. Two women who had agreed to participate in Group G (Women, younger, lower SES) did not attend the focus group, and one woman from Group E (Women, older, upper SES) did not attend.

6.2.3 The procedures taken
The focus groups were held in a number of venues:

- Grovedale Community Centre
- Cloverdale Community Centre in Corio
- Kardinia Senior Citizen's Centre and
- Club Italia.

Prior to the discussion commencing, each person read a plain language statement and then signed a consent form indicating they were giving their informed consent to their participation. A blank copy of the consent form is included in Appendix C. All participants were reminded that the discussions were confidential and that the identity of participants would not be kept with the tapes or transcripts of the discussions. A facilitator conducted each focus group aided by one assistant. The facilitator asked each
Table 6.2  Demographic Characteristics of the Focus Group Participants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>37 (58%)</td>
</tr>
<tr>
<td>Female</td>
<td>27 (42%)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>20 – 29 yrs</td>
<td>3 (5%)</td>
</tr>
<tr>
<td>30 – 40 yrs</td>
<td>17 (27%)</td>
</tr>
<tr>
<td>41 – 49 yrs</td>
<td>8 (13%)</td>
</tr>
<tr>
<td>50 – 59 yrs</td>
<td>14 (22%)</td>
</tr>
<tr>
<td>60 – 69 yrs</td>
<td>15 (23%)</td>
</tr>
<tr>
<td>70 yrs or over</td>
<td>7 (10%)</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
</tr>
<tr>
<td>Employed full-time</td>
<td>9 (14%)</td>
</tr>
<tr>
<td>Employed part-time</td>
<td>9 (14%)</td>
</tr>
<tr>
<td>Seeking work</td>
<td>4 (6%)</td>
</tr>
<tr>
<td>Home duties</td>
<td>12 (19%)</td>
</tr>
<tr>
<td>Retired</td>
<td>19 (30%)</td>
</tr>
<tr>
<td>Student</td>
<td>2 (3%)</td>
</tr>
<tr>
<td>Disabilities pension</td>
<td>6 (9%)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (5%)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>Primary</td>
<td>16 (25%)</td>
</tr>
<tr>
<td>Secondary</td>
<td>32 (50%)</td>
</tr>
<tr>
<td>Tertiary</td>
<td>23 (23%)</td>
</tr>
<tr>
<td>No answer</td>
<td>1 (2%)</td>
</tr>
</tbody>
</table>

group to discuss a number of questions. The two groups comprising individuals from an Italian background were conducted in English. The facilitator for these groups was fluent in Italian and familiar with Italian customs. Each focus group discussion was
tape recorded and transcribed for analysis. The duration of each focus group discussion was approximately one and a half hours.

6.2.4 The questions asked

The facilitator asked a series of questions that had been pre-determined. While there was the opportunity for free flowing exchange between participants, at an appropriate time, the group was guided back to the question structure that was as follows:

- What do you value most about the public health care system?

- Does the health system meet your needs?
  
  If not, where are the shortfalls?

- What is the major issue facing the health system?

- What should be the major priorities of the health system?

- Is it more important to spend money on:
  
  Hospitals or on community based services?
  
  Curing illness or educating the public about health risks?
  
  Intensive care units for people over 80 or on cancer research?
  
  Open heart surgery or in the care of people with renal problems?
  
  Saving a premature baby or saving the mother?

- Should any people be treated differently because of their age, personal situation, or behaviour?

- Are there times when medical professionals should not do everything they can to prevent death?

  (This does not mean euthanasia or assisting people to die but refers to discussing the non-initiating of treatment when a person is very ill.)

- Who should determine the priorities of the public health care system?
  
  Should the public be involved?

- Are there any other matters you would like to raise?
6.3 Data Analysis and Results

Each focus group session was recorded and then typed to form a comprehensive transcript of the session. These transcripts formed the basis from which data were extracted to accord with the major themes of the study. The analysis of the focus group transcripts was performed manually. Initially lists of the main themes emerging in response to each question or issue were developed. Comments made by participants in each group were assigned to the appropriate theme. This information was then summarised across all of the groups.

The results are presented as responses to the key areas of inquiry about the public health care system. These areas were selected as they reflect the major study areas of the research and provide a useful means of analysing the data. These are listed as:

- Values
- Shortfalls
- Issues
- Priorities
- Funding alternatives
- Equal access to care
- Options to aggressive care
- Decision making

The qualitative nature of this research required judgments about the particular area of inquiry where comments were directed from the participants. Responses were clustered according to these areas and where there were multiple areas from the one reference, these were recognised in each cluster. The results are presented using these key areas of inquiry about the public health care system.

In this chapter, the opportunity has been taken to quote extensively from the transcripts. The inclusion of primary source data enables a far more realistic impression of the discussion that occurred and substantiates the emerging trends and issues evolving from the discussion. These quotes are inset and italicised. Blank lines within the quotes indicate different participants are speaking while bold text within the quotes indicates the facilitator is speaking.
From time to time, emerging trends are identified that aim to draw out particular points from the section being presented. These comments will be in a different typeface (Comic Sans MS).

6.3.1 Values
Participants were asked what they value most about the public health care system. The responses identified seven separate issues that were:

- Quality of service and staff;
- Knowing it is there;
- Availability;
- It’s free;
- Hospice;
- The Geelong Hospital;
- Other areas valued

These responses are now summarised under the respective issue.

6.3.1.1 Quality of service and staff
This was mentioned by six of the groups but not by Group C (Men, younger, lower SES); or Group G (Women, younger, lower SES).

...we are very lucky to be in this country and very lucky to have the system that we have, nothing is a hundred percent prove (sic) but we should realise that this, today’s society and look back on the people that they’ve got nothing at all, we got at least, good hospital, good nursing, good doctors, the very best in the world. (Group D: Italian men)

Worldwide the quality of the healthcare in Australia compared to a lot of countries is exceptionally high. (Group B: Men, younger, upper SES)

As soon as we were transferred to Geelong Hospital, to the Urology Unit in outpatients, it was wonderful. The treatment was wonderful, while in hospital his care was wonderful... (Group E: Women, older, upper SES)
6.3.1.2 Knowing it is there

Participants in five of the groups mentioned this but not Group D (Italian men); Group F (Women, older, lower SES); or Group H (Italian women).

You just know it’s there, and you feel you will be looked after no matter what is wrong with you. Because they obviously don’t leave you, they don’t just leave you and not look at you. But um, I guess just a sense of security you must value somewhere along the line, knowing that no matter what time of day you do go in...just that security, that even if you don’t have any cover, or anything like that, you can go in, and generally you will be looked after. (Group G: Women, younger, lower SES)

Knowing it’s there if something does happen, right. (Group A: Men, older, upper SES)

6.3.1.3 Availability

This is similar to ‘knowing it’s there’ but some spoke specifically of the availability of services in Geelong. This was mentioned by four groups including Group E (Women, older, upper SES); Group F (Women, older, lower SES); Group G (Women, younger, lower SES); and Group H (Italian women).

... than you would have seen say twenty years ago, you know, patients had to go to Melbourne and now they do all that here now don’t they.

Geelong instead of going to Melbourne.

Heart operations, having them here and they actually have them in Geelong.

(Group H: Italian women)

If your need is such that you need expert attention it is available, sometimes it’s not explained to you properly because there isn’t time, but it’s available...

(Group F: Women, older, lower SES)
6.3.1.4 It’s free

This was mentioned by four groups including Group A (Men, older, upper SES); Group C (Men, younger, lower SES); Group E (Women, older, upper SES); and Group G (Women, younger, lower SES).

I think one of the things that is very important is that it caters for people who economically might not be able to afford health care. And I think that health care’s vitally important, and that everyone, no matter what socioeconomic group they’re from has the opportunity to obtain good health services. It needs to be provided so that the rich and the poor have access to it. Especially, the poor are not left out because of money problems. (Group E: Women, older, upper SES)

It’s free.

Yes it’s free, that’s a good one. (Group C: Men, younger, lower SES)

6.3.1.5 Hospice

The hospice service was mentioned by four groups including Group A (Men, older, upper SES); Group B (Men, younger, upper SES); Group F (Women, older, lower SES); and Group H (Italian women).

Okay what is good about it in my experience that I had at .... months ago, what are really good and very nice health is hospice sisters that go home and that do a lot of help, they help. (Group H: Italian women)

District nurses out there they seem to do a fairly good job of it. The ones that go round to the cancer patients.

Hospice?

Yeah hospice yeah. (Group B: Men, younger, upper SES)
6.3.1.6 The Geelong Hospital

This was specifically referred to by three groups – all in the older age group: Group A (Men, older, upper SES; Group E (Women, older, upper SES); and Group F (Women, older, lower SES).

*Just knowing that the Geelong Hospital is there. It's a great institution...*

*(Group E: Women, older, upper SES)*

6.3.1.7 Other areas valued

Other aspects of the public health care system mentioned as valued by participants were:

- the Grace McKellar Centre (Group A: Men, older upper SES; Group E: Women, older, upper SES);
- emergency care (Group E: Women, older, upper SES; Group F: Women, older, lower SES);
- Hospital in the Home (Group E: Women, older, upper SES);
- community based services (Group E: Women, older, upper SES);
- cancer care (Group H: Italian women); and
- support groups (Group G: Women, younger, lower SES).

The types of health services mentioned in each focus group provides some indication of the health services utilised or valued by participants. Table 6.3 (next page) presents the services mentioned in two or more groups.

6.3.1.8 Emerging Trends

The focus groups valued the fact that a health service was available to the Geelong community and that it was available, accessible and free. Most groups acknowledged the quality of services delivered and the clinical excellence in medical and nursing staff. Services valued tended to be in three groups. The highest priority services were in the acute areas including emergency and critical care services. The next group considered the sub-acute areas of rehabilitation and after care. The final group covered the more community based services.
<table>
<thead>
<tr>
<th>Service mentioned early in discussion</th>
<th>No. of groups mentioning service</th>
<th>Groups mentioning service</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Geelong Hospital or &quot;the hospital&quot;</td>
<td>7</td>
<td>NOT Group B (Men, younger, upper SES)</td>
</tr>
<tr>
<td>Doctors</td>
<td>7</td>
<td>NOT Group A (Men, older, upper SES)</td>
</tr>
<tr>
<td>Emergency services</td>
<td>6</td>
<td>NOT Group B (Men, younger, upper SES); Group H (Italian women)</td>
</tr>
<tr>
<td>Specialists</td>
<td>6</td>
<td>NOT Group F (Women, older, lower SES); Group G (Women, younger, lower SES)</td>
</tr>
<tr>
<td>Dental services</td>
<td>6</td>
<td>NOT Group E (Women, older, upper SES); Group G (Women, younger, lower SES)</td>
</tr>
<tr>
<td>Grace McKellar Centre</td>
<td>5</td>
<td>NOT Group B (Men, younger, upper SES); Group C (Men, younger, lower SES); Group G (Women, younger, lower SES)</td>
</tr>
<tr>
<td>Aged care</td>
<td>5</td>
<td>NOT Group A (Men, older, upper SES); Group C (Men, younger, lower SES); Group F (Women, older, lower SES)</td>
</tr>
<tr>
<td>After care</td>
<td>5</td>
<td>NOT Group B (Men, younger, upper SES); Group C (Men, younger, lower SES); Group H (Italian women)</td>
</tr>
<tr>
<td>Education</td>
<td>4</td>
<td>Group B (Men, younger, upper SES); Group D (Italian men); Group G (Women, younger, lower SES); Group H (Italian women)</td>
</tr>
<tr>
<td>Drug &amp; alcohol</td>
<td>3</td>
<td>Group C (Men, younger, lower SES); Group E (Women, older, upper SES); Group G (Women, younger, lower SES)</td>
</tr>
<tr>
<td>District nursing</td>
<td>3</td>
<td>Group C (Men, younger, lower SES); Group E (Women, older, upper SES); Group F (Women, older, lower SES)</td>
</tr>
<tr>
<td>Mental health</td>
<td>2</td>
<td>Group E (Women, older, upper SES); Group G (Women, younger, lower SES)</td>
</tr>
</tbody>
</table>

(Cont.)
<table>
<thead>
<tr>
<th>Service mentioned in discussion</th>
<th>No. of groups mentioning service</th>
<th>Groups mentioning service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research</td>
<td>2</td>
<td>Group B (Men, younger, upper SES); Group D (Italian men)</td>
</tr>
<tr>
<td>Dietary services</td>
<td>2</td>
<td>Group C (Men, younger, lower SES); Group F (Women, older, lower SES)</td>
</tr>
<tr>
<td>Prevention</td>
<td>2</td>
<td>Group B (Men, younger, upper SES); Group D (Italian men)</td>
</tr>
<tr>
<td>Ambulance services</td>
<td>2</td>
<td>Group C (Men, younger, lower SES); Group D (Italian men)</td>
</tr>
<tr>
<td>Ancillary services</td>
<td>2</td>
<td>Group D (Italian men); Group F (Women, older, lower SES)</td>
</tr>
<tr>
<td>Community health centres</td>
<td>2</td>
<td>Group C (Men, younger, lower SES); Group G (Women, younger, lower SES)</td>
</tr>
<tr>
<td>Medications</td>
<td>2</td>
<td>Group B (Men, younger, upper SES); Group H (Italian women)</td>
</tr>
</tbody>
</table>

Mental health services, illness prevention and research did not take prominence with many groups indicating a far greater awareness of the issues likely to confront participants personally. This conclusion highlights the difficulty that is faced by asking individuals to consider issues where knowledge and understanding of the health system is limited.

### 6.3.2 Shortfalls

Each group was asked if the public health care system met their needs and if not, what do they think are the shortfalls in the system. The responses identified eleven areas of shortfall and these were:

- Waiting;
- Concerns about doctors;
- Staff shortages;
- Funding shortages or beds closing;
- Dental;
- Lack of information;
- Concerns about interns in emergency;
- Shortage of detoxification (detox) places;
- Lack of men’s health services/research;
- Over use of the system; and
- Other concerns

These are more fully discussed as follows:

6.3.2.1 Waiting

All groups mentioned waiting. Some differences were identified in the type of waiting, but most groups mentioned more than one type. Group E (Older women, upper SES) was the only group to mention only one type of waiting and that was for elective surgery. The most frequently mentioned types of waiting were for elective surgery, emergency treatment, dental care, and for an appointment with a specialist.

*Just the waiting time to go for an operation.*

*Yeah.*

*You've got a waiting time just to see a G. P.*

*Yeah well that's true too.*

*Like looking at dietary and all those little sub things in the whole Barwon system, you've still got to wait.* (Group F: Women, older, lower SES)

*Yeah I think especially in public hospitals, casualty, they keep you waiting too long, should be more doctors in casualty working and .... ... for four or five*
hours ... You have a pain or something like that and waiting to see a doctor.
(Group C: Men, younger, lower SES)

... the long waiting list for operations in the hospital. (Group G: Women, younger, lower SES)

I had to come back to Geelong to see a specialist and it took a month and a half to get to see him. I know it was only a minor thing but I just felt that it was a long delay. There seemed to be a long waiting list to see specialists. (Group A: Men, older, upper SES)

The younger, lower SES women had different experiences regarding waiting times for general practitioners:

I can handle the waiting lists. Fair enough doctors have plenty to do while they're in hospital. But I really can't see the point why they book about 20 people in one time slot and then complain that they don't get out in time.

I get that just seeing my own GP. I book it, or they book it, and you still sit there for an hour.

Yes I agree.

So really when you're saying, you've got to wait, you more or less know you've got to wait, so you bring a book, don't you?

But it is annoying.

That's the thing, that, I don't know if I've got a really good GP or not, but my GP, you book in at that time, and you get in at that time, and then you're out of there.

I've never had that. (Group G: Women, younger, lower SES)

6.3.2.2 Concerns about doctors

All groups raised concerns about doctors. Comments ranged from stories of specialists being rude and lacking people skills, to doctors not spending enough time with each
patient. The least vocal group on this issue was the younger women, lower SES group where one woman described some doctors as “quacks”.

Some of the doctors also don’t have people skills they just treat you like a part of cattle, like prong you with this, stick this up you, or you know catch, thanks for the money.

Yep.

No communication.

Yeah. (Group C: Men, younger, lower SES)

The treatment we got from specialists - I should have gone to Stan but I didn’t - was absolutely, you know, I can’t believe the way they treated us and treated my father. Like the way they spoke to us was just, I couldn’t believe it, it’s the year 2000 and we’re being spoken to like that. We were spoken down to. (Group E: Women, older, upper SES)

Most doctors rush you through

Yeah its time constraints

Oh especially with bulk billing clinics.

Oh I go to a private doctor and I was there for 10 minutes, and it was yeah all right see you later.

They always seem to put it down like it’s not as major as what you thought it was and you have been wasting my time and I have so many people to see today and you’re not a top priority.

Yeah they need more time and space the patients out a bit more cause I don’t know its like a production line. (Group B: Men, younger, upper SES)
... and when you go to surgery instead listen your problem, that's what you're there for, they seems like ready boom, and it's the next one, they just shove you just like ...

Animal.

Like it's a piece of meat ... (Group D: Italian men)

6.3.2.3 Staff shortages

All groups except Group B (Men, younger, upper SES), mentioned staff shortages. Some individuals suggested that the staff were overworked, and that it was the system not individuals at fault.

Once in there, the funding cuts had affected it because there was not enough staff, particularly in the cardiac section, to run it. The people who were in there were all stressed, they couldn't give the quality care that they wanted to do ... (Group A: Men, older, upper SES)

... what I would like to see is more staff in the hospital because when you, if you happen to go in hospital for emergency you got wait there for five, six, seven hours sometimes because they're short of nursing and doctors, that's what I would like to see improvement on, more doctors in the hospital than what it has. (Group D: Italian men)

But they said the people who worked for them, and were trying to do their best and were run off their feet. So they realised it was the staffing situation, not the quality of the staff. That they could have done more but they couldn't fit more into their day. (Group E: Women, older, upper SES)

6.3.2.4 Funding shortages, or beds closing

Mentioned by all groups except one, Group B (Men, younger, upper SES).
It's not just nurses and doctors, it's the whole thing with the funding. It's the cleaning services, the food services. They've been cut back drastically at the Geelong Hospital recently. (Group E: Women, older, upper SES)

... every year there's more people coming into the public health, but every election it's getting cut back and I think you know if they keep closing beds, closing wards, where's it leaving the people. (Group F: Women, older, lower SES)

6.3.2.5 Dental

Problems with dental services were mentioned by all groups except Group G (Women, younger, lower SES). Some participants spoke about problems with waiting for dental services, others about the cost with others mentioning the limited services available.

You go to the community health centre and have your teeth done, get fillings, a filling is fine but my filling has fallen out three times or four times and now they say I've got to either have a cap, a pin put in it and a cap or have it out and they don't do it there. (Group F: Women, older, lower SES)

Two years if you want to put in new teeth or ...

... every time you go you've go to pay twenty dollars, I mean pensioner, I've got a friend of mine, she's a pensioner, she has to have some teeth ... and they said to her okay come and wait and get your first one, that will be twenty dollars and the next week you come and get the other one and it's another twenty, in all by the time she's finished she's paid eighty dollars at the Geelong Hospital. (Group H: Italian women)

Some participants were bemused by the limited dental services available in the public system:
... to think that a part of the human anatomy like dentures or teeth is not considered part of the equation is nothing short of extraordinary ... (Group A: Men, older, upper SES)

Participants in two of the groups described dentures being lost ...

...when she was admitted on one occasion, she lost her bottom denture. So, to me it wasn’t a major problem but to her it was a big problem. You know, and I said I’d speak to the sister in charge and so on. So I did that. Anyway, she was discharged without this bottom denture...(Group E: Women, older, upper SES)

6.3.2.6 Lack of information

Five groups but not Group B (Men, younger, upper SES); Group D (Italian men); or Group E (Women, older, upper SES) reported this as a problem.

I’d like to make one comment and specifically about Barwon Health, they have some fantastic services available covering very diverse area and yet the public are generally not aware of what is available and I think the amount of publicity put out to the public is totally inadequate.

I agree with you but the problem is not because they’re not putting the publicity out, the problem is people are not reading the publicity or hearing it. (Group A: Men, older, upper SES)

... a lot of us don’t know where these places are and there’s no directory or no pamphlet, no booklet to tell us what is in that picture, what departments, some departments don’t even know that other department exists. (Group C: Men, younger, lower SES)

We can’t seem to find any support there as in, you know, I mean he can do everything else, but there’s no real support for, apart from, you have to go hunting for it, for information. There’s nothing

Readily available
Yeah, you know, it's just ridiculous.

So it's just getting the information, finding whether the services are there?

Yeah, they're not publicised, sort of thing. (Group G: Women, younger, lower SES)

6.3.2.7 Concerns about interns in emergency

Concerns about interns working in emergency and being overworked or underqualified were mentioned by three groups including: Group A (Men, older, upper SES); Group C (Men, younger, lower SES); and Group G (Women, younger, lower SES).

... Geelong Hospital in emergency, you're not having a registered doctor, a lot of them are just interns, and it makes you feel very insecure, and you don't feel as though you're getting the help that you need. (Group G: Women, younger, lower SES)

If I end up in hospital late at night I really don't want to be handled by a doctor who hasn't slept for the last twenty hours, the length of times that the interns have worked is in my view inappropriate. (Group A: Men, older, upper SES)

6.3.2.8 Shortage of detoxification (detox) places

Two groups, Group C (Men, younger, lower SES) and Group E (Women, older, upper SES), mentioned this.

I mean, you need detox places for drug people, which is as far as I know is very poor in Geelong. But that's something - we've got lots of drug addicts, and they want to get off the drugs, but they haven't got any, there's no help for them, so they're back on the drugs, and can't do it on their own. (Group E: Women, older, upper SES)
6.3.2.9 Lack of men’s health services / research

Two groups mentioned this including Group B (Men, younger, upper SES); and Group F (Women, older, lower SES).

Something really radical ... favoured towards women, if men could get pregnant we’d get a better deal.

That’s right there is more research into breast cancer than there is into prostate cancer.

As a man, this will be biased, umm I have the feeling that within the media and within society it’s becoming politically correct to get excited about women’s health issues and certainly the women’s lobby do get very excited about women’s health issues and most of the men’s health issues hardly get an airing at all cause there aren’t many men throwing condoms at the Prime Minister ...

(Group B: Men, younger, upper SES)

6.3.2.10 Over-use of the system

This was mentioned in two groups by Group B (Men, younger, upper SES) and Group D (Italian men).

... one is overuse of public hospital, the public system because when there was private health insurance everybody paid, young, old, it was all right. Now as soon as the Medicare came in I noticed the last twenty years any (all talking) ... going backwards because everybody is dependent on the public system, ... if that was for old, for pensioners and sick like in the old years, but now everybody is ...... on it, that’s all right. (Group D: Italian men)

6.3.2.11 Other concerns

Other areas of concern mentioned by only one of the groups included:

- money spent on the appearance of buildings rather than on services;
- a lack of coordination in the system with patients needing to communicate the same information many times;
- early discharge from hospital;
- administrative problems in dealing with bureaucracy;
• diabetics having to pay for needles;
• golden staph present in patients;
• uncertainty regarding the future of the Grace McKellar Centre;
• not enough after care services;
• mental health services being slow to respond; and
• the need for interpreters when medical professionals speak with patients from a non-English speaking background.

6.3.2.12 Emerging trends
The focus groups identified waiting times; concerns about doctors and funding issues as the major shortfalls of the public health care system. Funding impacted on staffing levels and dental services. While it was expected that access would be an issue, particularly for elective surgery, the commonality across most groups about the attitudes of doctors and the poor supply of dental services was quite surprising. These major findings have helped inform the development of the interview schedule for the community survey described in Chapter 7.

Concerns about the lack of information reflect a view that even though there may be information being circulated, it is mainly unintelligible to the community, as represented in the majority of focus groups.

The comments about the seniority and ability for junior medical staff to cope in the emergency department at The Geelong Hospital co-incided with a campaign by the Australian Medical Association to improve the hours of work in all public hospitals and the comments may reflect this.

Interesting comments were made about the over use of the system and this may be alluding to the notion that if payments are not made then the system is prone to be rorted. This libertarian approach was a minority view and needs to be balanced against the values that were clearly articulated earlier in this report.
6.3.3 Issues

The groups were asked what they saw as the major issues facing the public health care system. The two main issues that emerged were:

- Lack of staff and / or a lack of money
- Issue of the ageing population.

6.3.3.1 Lack of staff and / or a lack of money

This response was the most common to the question of what is the major issue facing the health system, mentioned by six groups but not by Group D (Italian men) or Group B (Men, younger, upper SES). Some participants referred to the role of politicians or the Government in these shortages.

Lack of doctors.
Lack of money
Understaffed. (Group C: Men, younger, lower SES)

The politicians.
Lack of staff.
Money, money they’re going, the staff. (Group A: Men, older, upper SES)

Government

In what way?

They’re cutting all the funds, the schools, the health system; they’re cutting everywhere. (Group G: Women, younger, lower SES)

6.3.3.2 Issue of the ageing population

Participants in two of the groups including Group E (Women, older, upper SES); and Group B (Men, younger, upper SES), referred to the issue of the ageing population.

Perhaps with the population aging, the life expectancy is getting older.
Considering that people are living longer but they are not necessarily healthier so that there is going to be a greater emphasis on the system to prop them up I guess while they are alive they are still going to need a lot of care and that’s linked sort of to people paying tax I guess as well, there will only be a number of people working and a number of people on benefits and sort of a system to pay for all this and an expectance that it is going to be there and not going to necessarily have the money or the means to pay for it. (Group B: Men, younger, upper SES)

6.3.3.3 Other issues
Two groups, Group A (Men, older, upper SES); and Group E (Women, older, upper SES) suggested there were too many chiefs and not enough indians. Two groups saw waiting times as a major issue (Group B: Men, younger, upper SES; Group C: Men, younger, lower SES); and mentioned aged care as an issue (Group D: Italian men; Group G: Women, younger, lower SES). Things mentioned by one group as an issue included: administrators lacking compassion (Group E: Women, older, upper SES); country centres closing down so others are overloaded (Group F: Women, older, lower SES); nursing homes (Group H: Italian women); and informing people what is available (Group H: Italian women).

6.3.3.4 Emerging trends
Funding of the health system is a recurring theme whenever and wherever issues about health systems are raised. An underlying theme of this thesis is also about this issue. If funding was not an issue then there would be less need to consider priority setting processes as everyone could receive all the services they needed. The awareness of the focus groups about this issue is an indicator of the publicity that it attracts as many of the comments reflected the very real problems that funding pressures dictate.

The other major issue of the ageing population also has received a great deal of coverage in the media and is a matter very relevant to all members of the community who have a relative, friend or are themselves confronting old age. The
fact that only two groups raised this suggests that there was a strong emphasis on the funding issue as the primary issue to be resolved.

6.3.4 Priorities

Participants were asked what should be the major priorities of the health system. The three priorities mentioned were:

- Staffing and funding;
- Aged care; and
- Mental health

6.3.4.1 Staffing and funding

The issue of staffing and funding also featured when groups were asked what should be the major priorities of the health system. Five groups mentioned this but not Group B (Men, younger, upper SES); Group E (Women, older, upper SES); or Group G (Women, younger, lower SES).

More staff.

More staff?

Yeah be it office staff, nursing staff, medical staff, you know, surgeons, doctors. I think more funding but I think with the Victorian Government perhaps it’s they should spend it on some their .... I think. (Group F: Women, older, lower SES)

Staffing and it’s not just in the public health, it’s private health as well. The pressures that are brought to bear on those who are left to do the work, I had first hand experience of this, such that people are under great stress in a situation where people’s lives are at risk, and that shouldn’t happen in a society like you’ve just stated and in my opinion the way that that can be overcome is by taking the stress off them, by not putting the pressures on them to be to do
outside what they’re, a normal person should have to do. (Group A: Men, older, upper SES)

6.3.4.2 Aged care

Aged care was mentioned as a priority by five groups but not Group B (Men, younger, upper SES); Group D (Italian men.); or Group F (Women, older, lower SES). However, two of the groups who did not mention aged care as a priority discussed it as an issue. These were Group B (Men, younger, upper SES); and Group D (Italian men).

Look after the elderly.

Affordable health.

Just concentrate a bit more on the elderly and that. (Group C: Men, younger, lower SES)

Probably the disabled and the elderly. And then the general, you know, we can basically, get by or we can wait. You know, I think that the priorities should be the children and the elderly.

Yeah the children and the older people.

Yes. (Group G: Women, younger, lower SES)

6.3.4.3 Mental health

Mental health was mentioned as a priority in two groups (Group E: Women, older, upper SES; Group G: Women, younger, lower SES). The quote illustrates strong agreement among participants in one group.

So more mental health type services?

Yeah, yeah.

Because they say 1 in 4 isn’t it, 1 in 4 people actually suffer from some sort of depression or...

That depression’s a big one isn’t it?
It’s real big.

You don’t know whether they’re just depressed for a little while or whether it’s actually a long term thing.

Yeah, major.

And if they’re dismissing it, they can go on and cause real havoc at home.

(Group G: Women, younger, lower SES)

6.3.4.4 Other priority areas

Areas mentioned by two groups as a priority included:

- reduce waiting times (Group F: Women, older, lower SES; Group H: Italian women);
- prevention (Group B: Men, younger, upper SES; Group H: Italian women);
- research (Group B: Men, younger, upper SES; Group D: Italian men); and
- children’s or young people’s health (Group B: Men, younger, upper SES; Group H: Italian women).

Other issues mentioned in only one group as a priority included:

- the ambulance service (Group C: Men, younger, lower SES);
- educating young people (Group B: Men, younger, upper SES);
- the need for more drug and alcohol services (Group C: Men, younger, lower SES);
- providing an information booklet on services (Group C: Men, younger, lower SES);
- maternal health (Group E: Women, older, upper SES);
- services for people with disabilities (Group G: Women, younger, lower SES);
- education for medical staff (Group D: Italian men);
- doctors spending more time with each patient (Group F: Women, older, lower SES); and
- increasing the Medicare levy (Group D: Italian men).

6.3.4.5 Emerging trends

The priorities are consistent with the issues raised although it is interesting that there was no general view about specific services that should be given priority.

Aged care was raised by a majority of groups but other services such as mental
health, children and young people's health were mentioned by only two groups. This is a further reinforcement that the community needs to be made aware of the issues and conflicting priorities that do exist and it cannot be assumed that, in the absence of such information, knowledge will abound.

6.3.5 Funding alternatives

Generally participants showed little awareness of the need for decisions to be made about allocating health resources. A small number of participants in the two younger men's groups (Group B and Group C) did acknowledge the need for decisions about funding in the public health care system.

And at the end of the day, if you've got 10 of something and 20 people that want it, you can either auction it off to the highest bidder, or you can tell them all, we're going to open up the gate and start giving these things away tomorrow morning at 7 o'clock, and the first 10 that line up in the queue get it, and the other 10 don't. You can only ration a service one or two ways. You either make them stand in a queue or you auction it off to the highest bidder. And at the moment the system we use, is make them stand in a queue. (Group B: Men, younger, upper SES)

I guess it's up to the hospital administration in each hospital to divide up their resources isn't it, decide, so it's really up to the hospital administration beforehand. When they get each amount of funding every financial year to divvy up their resources however they see fit. (Group C: Men, younger, lower SES)

Each focus group was presented with a series of questions in which they must decide if it is more important to fund one type of activity or another. How participants discussed these questions is informative in terms of the values they hold.
6.3.5.1 Hospital versus community based services

Only two of the groups reached a consensus decision on one of these options being more important. Both of the lower SES women’s groups (Group F and Group G) opted for community based services.

Yeah, I agree there. Because people will go more to the community than the hospitals. You know, they’ll say oh I’m going to the hospital for such and such, whatever’s wrong with that person, and if you’re going to the other places, you can, they won’t feel that there’s bad inside them, and they’ll go and get help more quickly.

Less stigma.

Yes.

With the community services it’s more casual, rather than the hospital.

Well, yeah, that’s right.

And it’s probably community services like prevention, prevent things happening before they get to the serious stage. (Group G: Women, younger, lower SES)

Six of the groups agreed that both hospitals and community based services needed to be funded. However, of these six groups, four commented that developing community based services may reduce the demand on hospitals. Participants in Group H (Italian women) suggested that while both needed to be funded, as community based services get donations from people, more funds should perhaps go to the hospital. Group C (Men, younger, lower SES) argued that funds should go to the emergency department in the hospital and to drug and alcohol services in the community based area.

Well the hospital needs the money more, if there’s any extra money going, but I wouldn’t like to take money away from one to give it to the other. (Group A: Men, older, upper SES)
I know they’re both vitally important, but maybe by developing some more of the community services, it will relieve the pressure on the hospitals, and hospitals can put patients out of there, knowing they’re going to have good follow-up and not need re-admitting later because they weren’t kept in. (Group E: Women, older, upper SES)

6.3.5.2 Cure versus education

Three of the groups agreed that education was more important. These were Group C (Men, younger, lower SES); Group D (Italian men); and Group G (Women, younger, lower SES). Group C (Men, younger, lower SES) suggested that education should be in lay English, and there was no need for expensive TV commercials – pamphlets in letterboxes would be better.

Educate it.

Educate it.

Educate it.

Yep me too.

Yeah definitely.

Prevention better than the cure.

Prevention’s better than cure, N.?

Yes, we’re all doing a hundred percent education. (Group D: Italian men)

The other five groups commented that both needed to be funded, although most time was spent on discussing the pros and cons of educating the public.

Everyone is saying about education but you still have to concentrate on illnesses because people who were not aware of the prevention have got the illness so you need to be able to help them and try and cure them.

It’s a catch 22.
It goes both ways. (Group B: Men, younger, upper SES)

Five groups discussed the need for education for young people in particular but not Group C (Men, younger, lower SES); Group D (Italian men); or Group H (Italian women). One group (Group E: Women, older, upper SES) discussed the need to educate men in particular.

I think our education has to start in school. You can't educate, you can't tell somebody how to eat at sixty when their heart's bad, you have to start, the education has to start in the school. This is what you have to do for your lifestyle or this is how healthy (someone coughs) it doesn't mean you're not going to have a heart attack, I think education has to start younger. (Group F: Women, older, lower SES)

6.3.5.3 Intensive care for over 80's versus cancer research

Half of the groups, Group D (Italian men); Group E (Women, older, upper SES); Group G (Women, younger, lower SES), and Group H (Italian women) agreed that cancer research is more important. They cited reasons such as concern about the quality of life for ill people over 80; that at 80 they had already lived their life; that it is better to let the very old die peacefully and with dignity; and that cancer affects every age group. Participants in Group E (Women, older, upper SES) suggested people should be educated about death.

Well, as a younger person, not nearing 80, I question sometimes some of the medical work done on elderly people, I sometimes feel, and I think some of the elderly people do too, that their time has come and when the battle's too much. And I really question sometimes whether the money and time and resources that are spent in keeping a really elderly person alive is worth it. And it's not just from an outsider's view, I think it's often from the patient's view.

I agree.

Very well said C. (Group E: Women, older, upper SES)
Cancer. Cancer because cancer comes at any age.

Yeah.

Over 80...

Because once you’re over 80, you’ve lived your life.

Had a good innings.

Yeah, basically. (Group G: Women, younger, lower SES)

The other groups could not agree on one option over the other. Some suggested that cancer research was very important, but they could not exclude over 80 year olds from intensive care, particularly if they thought about individual people. Some participants viewed caring for the 80 year olds as a more immediate need with one participant from Group B (Men, younger, upper SES) arguing that people over 80 should be able to fund their own health care.

You can’t take that intensive bed. I’d hate to think I was 81 for instance, and needed that intensive care bed and they didn’t give it to me because they needed the money for research.

Or because you’re old.

I think you still have the right to live no matter how old you are. (Group F: Women, older, lower SES)

Well first of all you’ve got to meet people’s needs don’t you, so you’ve actually got to put the money into the 80 year olds because that’s the immediate need, like research is a secondary thing, you know what I mean, first you meet people’s needs and then what ever’s left over you put into research. I mean research is probably more important than the 80 year olds, but you’ve got to, you can’t make decisions like that, you’ve got to meet people’s needs and then do the secondary thing, which is research.
You wouldn’t argue if it was your 80 year old father. (Group C: Men, younger, lower SES)

6.3.5.4 Open heart surgery versus renal care

Seven groups could not decide on which area was more important. Many commented that the question should not be asked, or that they could not answer that question. In Group G (Women, younger, lower SES), several participants argued that open heart surgery was more important, because heart problems are more life threatening. One woman in this group misunderstood the question to be comparing open heart surgery with kidney transplants and argued that people could survive on dialysis. Most groups found this the most difficult of the funding alternatives presented to them.

So it goes against our very political system to even ask that question. (Group C: Men, younger, lower SES)

I don’t think there’s any comparison.

No way.

I think there is, they’re both most important.

They’re both important

You need dialysis and I need open heart surgery, neither of us should prioritise (Group F: Women, older, lower SES)

Oh that’s a hard one.

I’d say both.

You need both.

Yes. (Group H: Italian women)

6.3.5.5 Mother versus the baby

Participants were presented with a scenario where a child was born prematurely and needed a lot of care in order to survive. The mother also needed a lot of care to survive.
Each has an equal chance of surviving, but it is only possible to provide one with the necessary care.

Five of the groups unanimously chose the mother but three male groups did not: Group B (Men, younger, upper SES); Group C (Men, younger, lower SES); and Group D (Italian men). Reasons given in favour of the mother included the fact that she may have another child, that the premature baby may have problems later, that the child would not have a mother to care for it, that the mother may have other children to care for, and that the mother is a more valuable member of the family or community.

_I'd say the mother too. Because if it was a premature baby, there might be all sorts of problems, and a lot more requirements of the hospital and the system needed for that baby. And who would look after the child? If the father’s at work all day, and the child is it going to go to a relative, or into childcare? So I’d save the mother._

_The mother._

_Because the mother might have another baby that was full term. (Group E: Women, older, upper SES)_

_The mother would already have established bonds with everybody. (Group G: Women, younger, lower SES)_

All of the groups who were divided on this question comprised male participants. In Group D (Italian men), while most chose the mother, some could not decide. One participant commented on not being able to choose between his daughter and his granddaughters. In the two younger men’s groups (Group B and Group C), some participants chose the baby. Reasons given included the fact that the baby did not choose to be born, had their life ahead of them, and are new and fresh. Some in both groups could not choose, one participant cited seeing his baby born as a reason.

_What I’m saying is that the baby is going to, I’d say to save the baby if it came to the crunch, in other it was a choice that only one was going to survive, I’d_
say baby but I'd only say baby because the baby's entitled to whole life ahead
of it, you know what I mean, that sort ...

Plus you'd always have that memory of your girlfriend or wife or whatever.

Well the young mother had the choice as A said of getting pregnant and she
had some sort of life, the baby hadn't had any. (Group C: Men, younger,
lower SES)

There was some recognition that the decisions posed in the funding alternatives depend
on whether they are approached with a particular person in mind, or more objectively.

I think if it was your own wife you'd choose the wife. If it was someone else
you'd choose the child. So then the child would have a chance at a life as well.
But your own wife you'd think...

Well that's why I said that if it was my wife that's the way I'd go.

Yeah.

But if it was just someone else that you're making the decision for, I'd
personally choose the baby. (Group B: Men, younger, upper SES)

Some participants expressed concerns about their ability to respond to the questions
because they had difficulty in not personalising the issue.

I'm finding these questions really difficult to answer.

They are.

Because it's supposing that you are totally impartial and you've got nobody
with a heart problem, nobody with a renal problem, nobody that needs
community care, nobody that needs a hospital care. (Group H: Italian women)

Well, like you wouldn't have the bond that the mother's just had with the baby,
you know what I mean? The mother's carried that baby right through, so it's
only natural she's going to want that baby to survive. Where all her family and
everything would rather see her survive than the baby, do you know what I mean?

Yeah.

That's why I say from an onlooker's point of view, the mother, but from a mother's point of view it would be the baby, I know in my case it would be. (Group G: Women, younger, lower SES)

You'd be bad at those decisions because you'd be personal about it.

Exactly as you said, finance trouble of course, my family would always go in first, wouldn't yours? (Group C: Men, younger, lower SES)

6.3.5.6 Emerging trends

These forced choice questions or conjoint analysis techniques are useful ways to focus participants' attention on particular issues. Jan, Mooney, Ryan, Bruggemann, and Alexander (2000) have shown this technique to yield potentially policy-relevant information about community preferences for health services and its use. The first question sought to gain an appreciation of how the participants viewed community-based services as an option to acute inpatient care. The only groups where consensus was reached were the lower SES women’s groups and this suggests that they have had more to do with community health services than the others have. The debate in other focus groups suggested that there was a general lack of knowledge about community-based services.

The focus groups were unable to reach agreement on all but the last of the forced choice scenarios. The difficulty that they experienced was anticipated but the comments did tease out some views that suggested that hard choices could be made if there was sufficient information given. The groups were able to reach a view on the question of the mother or the baby with the majority opting to support the mother. The real issue is how the groups would vote if they were not
dealing with an issue in abstract but were considering an actual case that was well known to them personally.

6.3.6 Equal access to care
Each focus group was asked whether any people should be treated differently because of their age, personal situation or behaviour. The typical response to this question was initially that everyone should be treated the same but during the discussion that followed, some participants suggested that some people should in fact be treated differently.

6.3.6.1 Treat the same
The first response to this question in every group except Group G (Women, younger, lower SES), was that everyone should be treated the same.

It's very difficult to put yourself into that situation.

Pretty hard to play God isn't it. And I think if you're putting yourself in that position, I don't think anyone really has the right to do that, so I think you have to give equal treatment. Even if you consider that it's a total waste on one person and that person is going to benefit. (Group E: Women, older, upper SES)

No, we all human beings.

M. says no.

We all human being (all)

I agree.

Me too.

We're all the same. (Group D: Italian men)
6.3.6.2 Treat differently according to behaviour

Participants in seven of the groups gave at least some support to the notion of treating people differently if their behaviour had contributed to their health problem but this did not apply to Group D (Italian men). Within each focus group there was often disagreement about this issue.

Well my husband had heart surgery, he’d already stopped smoking for 16 years previously, but the surgeon who did his operation does not, or did not operate on smokers, people who hadn’t given up. If they’d given it up, fine, if they weren’t prepared to change their behaviour for own long term life, well why spend all that money on the heart surgery.

So you’re saying that’s a good idea?

Yeah.

I agree with it.

M, what do you think about that?

Oh I don’t think really they should make a choice, they’re there to look after you.

Regardless. (Group F: Women, older, lower SES)

Oh I personally would react, if I knew the full circumstances, I would react, and they were all equal in their need, then I personally would probably give the person who was not ...

Been causing it.

Yes, but that’s acting once again, that’s putting myself up as God and you can’t do that. (Group A: Men, older, upper SES)

Participants in one group discussed the extent to which an individual knows that they are endangering their health, with some suggesting this should be taken into account.
I don’t know in hospitals how close it ever gets to that point. But if you had 5 people who inflicted it themselves, I’d swing to the 5 people that didn’t. But it also depends on how, did they know that that was harming themselves. Like smokers, 50 years ago they thought it was good for them, so you’ve got to work out did they know it was affecting them. (Group B: Men, younger, upper SES)

Individuals in two of the groups, Group G (Women, younger, lower SES) and Group H (Italian women), suggested that people whose behaviour had caused their illness may in fact need more help because they have problems.

It would be difficult. Because maybe those people that are the high risk, they might be the people that really need the help, like if they’re alcoholics or you know.

Yeah.

Maybe that’s where you need to spend more on them. (Group G: Women, younger, lower SES)

6.3.6.3 Treat differently according to age
After discussion, at least some participants in all groups indicated that they would give preference to a younger person over an elderly person. To elicit this information, some of the groups were asked who they would give a kidney transplant to if there was only one kidney available and all had an equal chance of success. The choices were a teenager, middle aged person, or elderly person. The younger person was selected as they have their life ahead of them. In Group D (Italian men), some participants felt that a 50 year old man should get preference as he may be responsible for looking after his family.

Well it’s the same thing isn’t it. If it comes down to you’ve got an 80 year old and a 20 year old and one service, one spare liver or something like that then you sort of morally bound to give it to the twenty year old. (Group C: Men, younger, lower SES)
Yes, generally I'd go for the younger person.

Because...

Because they've got longer to live. They haven't fulfilled their dreams yet, whereas an older person has sort of got more runs on the board. (Group B: Men, younger, upper SES)

6.3.6.4 Other issues raised

In addition to the common themes presented above, there were issues raised in individual groups in response to this question. Individuals thought that:

- Very premature or severely disabled babies should not be treated (Group E: Women, older, upper SES);
- People on drugs could not be disregarded because they were contributing to their problem (Group E: Women, older, upper SES);
- People on drugs or selling drugs should not receive treatment (Group D: Italian men); and
- People in prison should be treated as lower priority (Group B: Men, younger, upper SES). The group where this was raised had a particularly lengthy discussion on this question.

6.3.6.5 Emerging trends

While some participants were prepared to discriminate according to behaviour and age, there was an overwhelming commitment to maintaining an egalitarian approach. Participants generally accepted that there was an argument in favour of discriminating in favour of the younger person compared to an older person but were reluctant to make a choice as they felt that they did not have a right to discriminate in this way. This was also true when lifestyle choices were postulated as a reason for discriminating against certain people. It was also evident that there were challenges in drawing participants down from the general proposition to a more particular proposition. The theoretical willingness to discriminate for example against an elderly person may be agreed in abstract but far more difficult to implement in practice.
6.3.7 Options to aggressive care

Participants were asked if there are times when medical professionals should not do everything they can to prevent death. It was explained that this was not asking about euthanasia or assisting death, but rather not doing everything possible to prevent a patient dying when they were very ill. In some of the groups, individual participants expressed an initial response that everything possible should always be done. However, the discussion in each group focussed on when it is preferable to allow someone to die and examples from personal experience were frequently raised. While each group was not asked to reach a consensus decision, the overall tenor in each group was that there are times when everything possible should not be done. There were several comments about this being a hard question.

Six main issues emerged during these discussions and are summarised as:

- The issue of choice or consultation
- Quality of life
- Okay to refuse treatment
- Let nature take its course / it’s God’s will
- Concern about resources
- Arguments in favour of treating

6.3.7.1 The issue of choice or consultation

In six of the groups but not Group C (Men, younger, lower SES) or Group D (Italian men), participants discussed the need for decisions about persevering with treatment to be made in consultation with the patient, or with the family if the patient was unable to be consulted. Some groups discussed who should be consulted. The responses indicated agreement that there are times when medical professionals should not do everything possible but that the choice should be given to those affected.

I would agree except from what X said, it seems to me that the choice of whether the family should be consulted as well as the patient has to be a choice, and in some circumstances you would not want the doctor to consult a
patient's family and in some circumstances you would not want the doctor to consult the patient but the family.

Horses for courses isn't it.

Yeah it's again one of these questions that are so very difficult. (Group A: Men, older, upper SES)

So sometimes it might be the person's choice not so much the family. What they decide, should be... If they're able to decide for themselves, yes. Their quality of life, whether they wish to go on. (Group G: Women, younger, lower SES)

6.3.7.2 Quality of life

When discussing this question, the patient's quality of life, or the notion of preventing the patient from suffering was the rationale for not always doing everything possible in five of the groups but not Group C (Men, younger, lower SES); Group B (Men, younger, upper SES); or Group E (Women, older, upper SES).

The patient say no. If they're so sick really I have seen and you know they really ... they just want to stop suffering and bring their release.

Yes.

They just want to stop suffering.

Yeah. (Group H: Italian women)

If you were in severe pain and they said there's no way of fixing you mate and you're going to be like this forever.

Well even if I was going to be a vegetable I'd want to be, to be honest I'd want to be out of it. (Group A: Men, older, upper SES)

6.3.7.3 Okay to refuse treatment

Four groups, Group A (Men, older, upper SES); Group D (Italian men); Group E (Women, older, upper SES); and Group F (Women, older, lower SES), cited examples
of cases they had known where patients, or their family, chose not to go ahead with treatment. These examples were presented in a way that confirmed that it is acceptable, in some circumstances, not to persevere with treatment.

My dad had a stroke, took (sic) to Geelong Hospital, and the doctor said we can revive him and you know he was pretty old then and I said let him die I said I want to remember the way he is now, I don’t want him to have all these, I don’t want to see him that he can’t feed himself or paralysed because he was paralysed right through and I always remember my dad like I see .... I don’t want to see him that he was you know, all you know they go funny and all that, I reckon that was very good and I just said to the doctor, don’t touch him, ... let him die and he took it, it was very hard for me to do it.

Cause yeah, though it would be worse if you’re going to stay home on a chair got to feed them and everything.

Would it prolong his life too long.

For sure. (Group D. Italian men)

(describes very ill father) but this one time he got a very bad cold and it was turning into pneumonia, he’d had it before but this time they asked mum, what do you want us to do, do you want us to treat him or just let it go and mum said that let it go, there’s no point in treating him, he didn’t know, well he knew mum, he didn’t know me until I sort of started speaking sort of thing... (Group F: Women, older, lower SES)

6.3.7.4 Let nature take it’s course / it’s God’s will
Consistent with the personal examples described above, participants in two of the groups, Group C (Men, younger, lower SES), and Group E (Women, older, upper SES) discussed either letting nature take it’s course or God’s will when discussing this question.

Letting nature take it’s course.
Yes. Exactly.

I think there’s a time when God takes a hand, and should be allowed to take a hand, yes.

I think the doctors allow that to happen. (Group E: Women, older, upper SES)

6.3.7.5 Concern about resources

Three of the male groups, Group B (Men, younger, upper SES); Group C (Men, younger, lower SES); and Group D (Italian men) discussed the problem of the resources involved in treating or maintaining very sick people.

It depends how much resources go into that patient, that you have to take away so many to keep one alive.

Are you saying take from other people?

Yeah if you’ve got to take from others to keep one, and the one’s got no hope, let them, you’re trying to keep them for only an extra six months where Joe A, B, or C, can live an extra couple of years and live okay, then I say cut it off. (Group C: Men, younger, lower SES)

When responding to this question, individual participants in two of these groups, Group B (Men, younger, upper SES), and Group C (Men, younger, lower SES) went as far as suggesting that life support machines should either be destroyed or not obtained.

But overall it’s the principle thing in this situation... Overall how much do some of these machines cost to keep a person alive, yet there are kids dying of malnutrition.

Agreed.

And dying of other things. Shouldn’t we just say let’s not bother owning those machines. Let’s just sell them, don’t bother developing. If someone gets that sick that they have to be put on one of those machines, stiff. (Group B: Men, younger, upper SES)
6.3.7.6 Arguments in favour of treating

Some individuals expressed the importance of doctors doing all that they can (Group B: Men, younger, upper SES; Group F: Women, older, lower SES; and Group H: Italian women) and some had personal examples of people choosing to have treatment when they were extremely ill (Group A: Men, older, upper SES; Group G: Women, younger, lower SES).

> If I was the one they were going to be treating I’d say yeah, for another year.

Yeah, but you’re 90.

So I’d be 91.

No you won’t, you won’t make it.

I think about 95% of the time it would be worth it. 5% of the time it wouldn’t, personally. (Group B: Men, younger, upper SES)

Now he lived 3 weeks after that. The operation was very successful, his heart was very strong, all the rest of it, he was able to pull through it fine. No one knew how long he would live for. It just so happened that it was only 3 weeks. But it gave us all hope, it gave him hope. And the bottom line was he wanted the operation himself. (Group G: Women, younger, lower SES)

6.3.7.7 Other responses

Other responses to the question of sometimes not doing everything possible to prevent death included:

- sometimes older people are prepared to go, and know when it is time (Group E: Women, older, upper SES);
- medical professionals should listen to the patient’s family who have known the patient longest and understand the patient (Group E: Women, older upper SES);
- medical professionals need to address very ill patients differently when discussing options (Group E: Women, older, upper SES);
- sometimes families hang on and can’t let go (Group E: Women, older, upper SES);
• it can be stressful for the family and friends of a patient seeing that person in a very bad way (Group C: Men, younger, lower SES);
• being in a coma is not really living (Group D: Italian men); and
• these decisions need to be made on a one-on-one basis, not as a mass decision (Group G: Women, younger, lower SES).

6.3.7.8 Emerging trends
The discussion enabled participants to assess whether they thought that there would be times when everything that could be done, should be done. The outcomes suggest that there are times where medical intervention may not be justified but the majority view was that this position should be reached in consultation with the patient or, if this was not possible, the family. Three groups noted the resource implications of continuing care under all circumstances and some more radical proposals were elicited. The implication in many responses was a desire to comply with the wishes of the patient and this will vary from a wish for continuing active treatment to a preference for no treatment at all. This highlights a need to have a better understanding of personal preferences prior to the onset of problems when, in some cases, it will be too late to determine.

6.3.8 Decision making
While participants generally agreed that the public should be involved in making decisions about the overall public health care system, they often showed a reluctance to consider some of the broader questions they were asked. Participants in every group commented on how hard it was to answer some of the questions. This was particularly the case in the series of questions about funding alternatives. At times this reluctance was evident in groans and a long pause after a question was asked, rather than in what participants said.

You can't answer that because ...

That's not a fair question.

Who's going to die first.
You can’t answer that because that’s moralising, that’s like playing God saying oh well you can die and you should live, you can’t ... (Group C: Men, younger, lower SES)

Thank goodness they’re decisions that we don’t have to make. (Group A: Men, older, upper SES)

Oh, well, you know, you’re forcing people to make a judgement on a question that wouldn’t happen in real life. So really, people don’t necessarily have to answer the question do they? I mean, it never comes down to that situation, so...

It’s hypothetical. (Group B: Men, younger, upper SES)

I can’t decide.

Yeah, I wouldn’t be able to. I mean there’s no way I’d be able to. Like if you had both people you couldn’t just decide all right, well you can, and you can go...

It’s a hard question. (Group G: Women, younger, lower SES)

### 6.3.8.1 How to approach decision making

While there was frequently a reluctance to make decisions, for example when the funding alternatives were presented, some individuals or groups suggested ways of approaching the decision. There was a tendency for the male groups to take a more conceptual approach to the questions asked and the female groups to be more focussed on the details of the particular issue. A small number of participants discussed the issues from a broader, more philosophical perspective. These perspectives can be grouped according to the four theories of justice discussed in Chapter 2:

- Egalitarian;
- Utilitarian;
- Libertarian; and
- Communitarian.
Participants did not necessarily support one approach consistently with many participants arguing that decisions need to be made on a case by case basis.

6.3.8.1.1 An egalitarian approach
This approach emphasises the equal distribution of both social benefits and burdens. Participants in seven groups indicated support for this view to some extent, often in response to the question asking if anyone should be treated differently. It was not supported by Group G (Women, younger, lower SES).

Well then you've got to try again as equitably as possible to try and spread the field and I know that you can't do that in reality, people are going to dip out and stuff but you've got to, that's got to be the goal is to try and meet everybody's needs within the resources that you have as best as possible and then try and spread the field with waiting lists, you understand what I mean, so that everyone misses out to the same degree and receives to the same degree so that it's not the heart patients that are getting fantastic treatment and ...
(Group C: Men, younger, lower SES)

Society expects particularly this sort of egalitarian Australian society in that we live in, generally says that every person is treated equally be they're young or old, slightly sick or very, very sick, they all have to get fixed and they're all entitled to equally good quality service and the society sees itself as having failed if it can't provide that service to all of them, that's my view. (Group A: Men, older, upper SES)

Pretty hard to play God isn't it. And I think if you're putting yourself in that position, I don't think anyone really has the right to do that, so I think you have to give equal treatment. (Group E: Women, older, upper SES)

6.3.8.1.2 A utilitarian approach
This approach can be summed up as "the greatest good for the greatest number". One of the most common approaches to funding decisions suggested by participants was to
look at the statistics to determine which diseases affected the most people. Five of the
groups mentioned this approach, including all four of the men's groups but not Group F
(Women, older, lower SES); Group G (Women, younger, lower SES); and Group H
(Italian women). There are examples in the transcripts of other members in the group
disagreeing with this type of approach.

*I guess to paraphrase it, what M's saying is you take the amount of money
you've got to spend and you look to see what gives the greatest good to the
greatest number of people. And make your decision that way. (Group B: Men,
younger, upper SES)*

*Say you've got a hundred percent, all right, and of that hundred percent, fifty
percent is cancer, thirty percent is heart, the balance is dialysis, well if you're
looking at funding it's just a way you might look at spreading it around.

You can't do it like that.

That's prioritising health, how do you prioritise health.

It's hard. (Group A: Men, older, upper SES)*

*If you can save one life by spending half a million dollars and you can save
twenty lives by spending that amount for like kidney dialysis and that sort of
thing then obviously you've got to stack it a bit more in favour of how many
lives you're saving but on the other hand you'll still try and meet the needs of
those heart patients. (Group C: Men, younger, lower SES)*

6.3.8.1.3 A libertarian approach
In this approach it is assumed that the market will provide all the services that are
necessary. A participant in only one group, Group B (Men, younger, upper SES),
articulated this view as appropriate. Others implied that this was not acceptable by their
strong advocacy for free health services as an important value of the public health care
system.
Simply for the fact of the preventative manner and the large number. I just think that an 80 year old person, because they're living longer, they're living... more financial and therefore they can invest more in their own health.

So it's not because of their age so much, you're saying because they're that age they should be able to pay for their own...

Almost. (Group B: Men, younger, upper SES)

6.3.8.1.4 A communitarian approach

As will be discussed below, there was considerable support for the notion that the community should have some input into health funding decisions. This was not mentioned specifically when discussing the funding alternative questions, or how to set priorities, but in response to questions on who should make the decisions.

Most participants remained grounded at a level where the detail of individual cases formed the basis for making decisions. Six of the groups argued that factors such as the urgency of the individual's need and the likely quality of life for the individual should inform the decision making process, but not Group B (Men, younger, upper SES); and Group H (Italian women).

I don't think that's a relative question because that's making us God over or judgement over things that are not, you know, we can't, well I can't give a decision on that based on I think it's a hypothetical question because each case is going to vary depending on it's merits. (Group A: Men, older, upper SES)

I think that the decision should be made on the basis of health,

Who has the greatest need at the time ...

Yes, yes, the health situation. (Group E: Women, older, upper SES)

... you've got to look at what the big picture is, is the person going to live or die at that time, that's split second and that's split second will tell you whether the heart person needs this heart operation now, or whether the renal now, and the other big picture is right, is the stress level and the pain of the patient,
right, when you have this person has renal thing, whether that person's in a lot of pain and agony and yet if you can fix that right, then that person's not going to have a life threatening thing but if that's a life threatening thing and it's easy to be fixed, then fix it. The same as with the heart right, if the heart victim comes in well you look at the stress. (Group C: Men, younger, lower SES)

Some cynicism was expressed about how decisions are being made, in three of the men's groups, Group A (Men, older, upper SES); Group B (Men, younger, upper SES); and Group D (Italian men). Participants suggested that illnesses or programs that are popular, supported by vocal groups, or seen as likely to win votes, are funded.

But the problem behind the question is really the people who make the decisions or make the decision on conditions that we may not approve of, for instance it's the popular program that usually gets the money, isn't it and at the moment cancer research is possibly at the top of the popularity list because everyone's aware of it.

And the heart would be over dialysis. (Group A: Men, older, upper SES)

I mean, the way I understand health decisions, allocations are made basically on which group is noisiest at the time, and what is seen to be the area of greatest need. (Group B: Men, younger, upper SES)

A participant in one group (Group B: Men, younger, upper SES) suggested that drug companies influence doctors' activities and that it is not in the drug companies' best interest for people to be healthy.

6.3.8.2 Who should be involved in decision making?

Each group was asked who should determine the priorities of the public health care system, or who should make the “big picture” decisions. The common theme during this part of the focus groups was that the people who make the decisions should have experience with the health system. This was the reason given why health professionals
or users of the services should be involved in the process and why politicians should not be responsible for decisions.

6.3.8.2.1 Health professionals
With one exception, being Group B (Men, younger, upper SES), all groups mentioned health professionals when asked who should make the big picture decisions about the public health care system.

\[ ... \textit{the professional people, people who have knowledge or maybe got a special method, or knowledge they should be ones who making decision, not any politician who had no experience whatsoever in health system, now they've become a Minister of Health and he has no, he or she has no knowledge whatsoever and they should never be given the job, it should be a professional medical ...} \quad \text{ (Group D: Italian men)} \]

\[ I \text{ really think the people who are in everyday life working in the profession know what's going on and I think that if you were to go and speak to all the doctors and say to them what they really need to run the hospital better from a health point of view, they would have a far better idea than the public servants that ..... the public service - all they're interested in doing is the dollar, where it goes, they're not so much interested in the actual care, I might be wrong in saying this.} \quad \text{ (Group A: Men, older, upper SES)} \]

\[ No \text{ you're right they're balancing books.} \quad \text{ (Group A: Men, older, upper SES)} \]

\[ The \text{ minister of health should have some, he should do it, but he shouldn't do it on his own, he should have, should do it in consultation with doctors and nurses.} \quad \text{ (Group F: Women, older, lower SES)} \]

6.3.8.2.2 Not politicians
Four groups, Group B (Men, younger, upper SES); Group C (Men, younger, lower SES); Group D (Italian men); and Group G (Women, younger, lower SES), stated it should not be politicians who decide the priorities of the public health care system.
I guess so yeah, I mean otherwise it's in the hands of politicians and you can't hand all, I mean I'd rather even hand it to administrators than politicians. (Group C: Men, younger, lower SES)

I mean, how involved should politicians be in health decisions? Cause won't they just, won't they just make decisions to get votes? (Group B: Men, younger, upper SES)

6.3.8.2.3 The public
Five of the groups mentioned some input from the public in decision making before being specifically asked about this but not Group C (Men, younger, lower SES); or Group D (Italian men). Group A (Men, older, upper SES) were asked about the public when first asked who should make the decisions.

I'd say the medical profession should investigate with the public before they make their decision. (Group H: Italian women)

Should be a wide range of the community, that way it doesn't compromise anyone. If you get someone from every group involved, and then you can work it out from there. It's not the one with the biggest wallet that says what will happen, it's everyone it affects. (Group B: Men, younger, upper SES)

The community. Shouldn't it be? The people in the community should have a say. You can't just elect someone and say you do it. There has to be input from the community. (Group G: Women, younger, lower SES)

In three of the four men's focus groups, but not Group D (Italian men), there was some concern expressed about involving the public.

...and I think that you've got to get, the public can't make the decision, it would be a real hotch potch if the public made the decisions, you'd never get a
decision and the public servants are making what they think is right... (Group A: Men, older, upper SES)

I don't think that's workable cause ...

Why not?

If you got a group of the public together and expected them to decide on questions like we've just been asked, you're going to be sitting there for six months you know.

Can't decide?

Yeah cause you're never going to decide between questions like that, you really have to get, it has to come down to cold hard economics doesn't it you know. (Group C: Men, younger, lower SES)

There were some suggestions about how to facilitate public involvement in decision making or what type of people should be involved.

I don't think it does have proper representation, I think it has the articulate middle class professional people on the board. To me that isn't a cross section of the community. So I think it needs to broaden its base. You do need the general ...

Yes, people who are using the system. (Group A: Women, older, upper SES)

But maybe we could educate people so that they did have sufficient knowledge to be able to make decisions. (Group A: Men, older, upper SES)

You'd have to do a bit research if you were that person.

You'd have to be ....... yeah of course you would, you wouldn't sit at home watching TV and then go to a meeting once a month. (Group F: Women, older, lower SES)
6.3.8.3 Options for community participation

6.3.8.3.1 Citizens' juries

Seven groups but not Group C (Men, younger, lower SES), were specifically asked about the idea of having a panel of citizens, or a citizen's jury to make health decisions. This was explained as a group of people who are given an issue to discuss, receive information on that issue, have access to experts and then are asked to decide the issue as representatives of the public. Most of the seven groups responded positively to this idea. One participant suggested it should happen only once a year (Group B: Men, younger, upper SES), while in another group (Group A: Men, older, upper SES) support for the idea was not unanimous. The other groups welcomed the idea, with some suggestions on who might be included.

... and I think that if you advertised for a member or even two or three members of the general public that they may not be aware of all the services that are available either, it needs to be someone with access to them. (Group F: Women, older, lower SES)

I think it's a very good idea.

Yes it is a good idea.

Yes.

The professionals get their feedback from the grass root or ...

Yes that's right.

They ...

M. did you have something to say?

I agree because ordinary people today have got the facility to know they are not professional but they do know what the professional can do through television, through news, through radios and everything helps and I think yeah why not, it's a good thinking. (Group D: Italian men)
Good idea.

Good, yeah.

Mmmm.

That sounds good to me.

It’s kind of what we were saying though, coming from the community. (Group G: Women, younger, lower SES)

6.3.8.3.2 Survey the public

Three groups suggested using a form or questionnaire to survey members of the public about their views (Group C: Men, younger, lower SES; Group E: Women, older, upper SES; Group F: Women, older, lower SES).

Yeah but not just one director, you know, it’s sort of like a board group of the directors that would sit down and say well look, yes this has got to go, yes this can stay, but also what I find is they should have a totally, get the Herald, the local paper, have a questionnaire, say three pages, questionnaire, let people write it out and then when they’ve got to postal vote thing, use that and just mark up these people and each question is under confidentiality in a way that they’re marked. (Group C: Men, younger, lower SES)

6.3.8.3.3 Like this group

Participants in five groups but not Group A (Men, older, upper SES); Group E (Women, older, upper SES); and Group H (Italian women), made some comment showing an awareness that the focus group itself involved members of the public in making decisions.

... to have people in the community list what they want, you know, same as you’re doing now and you have people like us put our remarks and then you can like if you’re the head of this community centre you can go to the forum and say well this is what our community needs and want ... (Group F: Women, older, lower SES)
I agree essentially with what M. was saying. That you empower people in the community. That you have an ongoing community consultation process, which is really what this is, isn’t it? (Group B: Men, younger, upper SES)

6.3.8.3.4 Combination of people
Participants in two groups, Group E (Women, older, upper SES) and Group F (Women, older, lower SES), specifically suggested that different types of people should be involved in making the decisions.

I don’t think it should come down to just one person making that decision, I think it should be a community, a committee with people from the health service, medical professionals, users of the services, a combination should decide where it’s going to go.

That’s what I think too. (Group E: Women, older, upper SES)

6.3.8.4 Emerging trends
The decision making processes were extensively canvassed and while there was some divergence of view, a common thread was to adopt an egalitarian approach that embraced the concept of community participation. It is notable that all the women’s groups and the Italian men supported community participation models of decision making. This means that three out of the four men’s groups did not support it. However, further specific questions about the form of community participation that may be implemented did elicit more positive responses with good support for citizens’ juries, focus groups and community surveys.

A feature of the responses about decision making was a general acknowledgment that health professionals were an integral part of the process. There was a need for the community participating in the process to be informed about the particular area under review and health professionals had to be involved in assisting if not making the decision. Accordingly, it seems appropriate that in
whatever system of decision making process, expert advice needs to be readily available.

The ambivalence towards politicians making decisions in these areas indicates the more popular community view about where politicians rank in society. The reality is that it is Governments that enable these decisions to be made and facilitate the very processes that are sought. The trend against politicians emphasises the need for care in any decisions affecting priority setting or rationing.

6.4 Concluding Observations

An advantage in using focus groups is the interaction between participants and the bringing together of people with quite diverse backgrounds. Within some groups, individual participants had quite different experiences of some services. For example, in Group E (Women, older, upper SES), a discussion occurred about after care services:

... but they put him in a taxi to bring him home. We said we'd get him but he said no, they've told me they'll send me home. He got put out of the taxi, not even taken to the front door at his daughter's. And the taxi just drove off. Now, a driver should have got out, a man who'd just had open heart surgery, helped him up the steps rung the doorbell, and seen that someone was there. (Group E: Women, older, upper SES)

I was lucky, I had all the backup services here with and home help and the Grace McKellar. And I also had people in the house so that I could have time out, because I was the carer, so I was looked after. It wasn't that they said okay your husband's the one that's had the problem. They also looked after me, Grace McKellar made sure that they had a co-ordinator who rang me to make sure that I was okay as well. I can only speak from experience, and I thought that it was absolutely fantastic. (Group E: Women, older, upper SES)

At times, participants changed their response to a question after listening to the discussion. The following quote was in response to a question asking who should have
a kidney transplant if three people needed it and only one kidney available: a 15 year old, a 50 year old, or a 75 year old:

Yeah I'd say the young one.

Yeah I'd say the younger too.

The younger one I think.

Anyway.

Fifteen?

Cause I've got my reasons.

That's it, you let him, that's all right and now he's this bloke.

... you need a transplant, a 50 year old person, so it's male or female, might have a family, sickness support the family and everybody else it wouldn't worry them they are going to accomplish ... the young person, not that I have anything against the young person, but he's got less responsibility to the family than the 50 year old.

That's why I go for the 50 year old.

Yeah I change my mind, I agree with him.

Agree with him too.

No, no I'm still on the 15. (Group D: Italian men)

I think something like this, you know, get people to come in and talk and you find a lot that way, you know, I agree now that community funding rather than hospital, if I'd just been listening. (Group F: Women, older, lower SES)

6.4.1 Awareness of Barwon Health

Some indication of the extent of participants' awareness of Barwon Health as an entity is obtained from an examination of the number of times individuals referred to Barwon Health and in what context. In general there appeared to be limited awareness of Barwon Health.
• Participants in two of the groups did not refer to Barwon Health by name at all (Group D: Italian men; Group H: Italian women).

• There was one reference to Barwon Health in two of the groups. One of these discussed the “Barwon Health Corio Community Health Centre” (Group G: Women, younger, lower SES) and another mentioned that Barwon Health is going down the path of services working together (Group B: Men, younger, upper SES).

• One group made two comments about Barwon Health (Group E: Women, older, upper SES), referring to the new Barwon Health centre in Newcomb, and asked who runs Barwon Health.

• Two groups made three references to Barwon Health. In the first of these, Group C (Men, younger, lower SES):
  • one person asked if anyone knew if Barwon Health had a dietician;
  • one discussed district nurses as part of Barwon Health; and
  • one commented that since “Barwon Health has been Geelong Hospital” they had noticed some improvement.

• In the other group, Group F (Women, older, lower SES):
  • one participant mentioned that she worked as a cleaner in Barwon Health;
  • one referred to “community centres and Barwon Health”, and
  • one thought they should advertise what is available in the Barwon Health area.

• One group made six references to Barwon Health (Group A: Men, older, upper SES), and indicated a greater awareness of what Barwon Health comprises.

6.4.2 Consultation with individuals
In addition to conducting the focus groups, the researcher spoke with a small number of individuals who were particularly interested in this research but did not participate in a
focus group. These included five people who responded to an article in *The Geelong Advertiser* about this study. Two individuals who participated in a focus group also provided some additional, written comments. The responses of these individuals to the questions asked in the focus groups were generally consistent with those of the focus group participants.

Several issues were raised by one or more of these individuals, which were not discussed by the focus groups. One of these issues was concern about the need for increased services to prevent suicide in our community, in particular youth suicide, and to provide counselling for families affected by suicide. Another issue was concern about the high number of adverse events in hospitals and the need to do more to prevent these. One individual expressed concern about the effect of a number of environmental hazards on the health of the public. The special needs of people from non-English speaking backgrounds was raised. One person also expressed concern at the lack of coordination between different services. It was suggested that stress and depression are major issues and that Barwon Health should be more proactive in providing and promoting mental health programs to the public. One person suggested that there should be an information centre or help line to assist the public in researching some health issues.

### 6.4.3 Limitations of the data

Data from the focus groups were sought to assist in the development of the interview schedule for the community survey. The recruitment of participants was difficult in some groups, notably the male, younger, upper SES group as there was a reluctance for some to accept the invitation. This may have skewed the profile towards a group that had some knowledge about the health field or Barwon Health in particular, a commitment to community participation or even a personal issue to pursue.

A feature of focus groups that is apparent is the tendency, on occasion, to engage in a "group think mentality". This occurs when one dominant participant puts a view so authoritatively that it becomes, quite quickly, the view of the group. The skill of the facilitators in this study has mitigated against this occurring to any extent likely to prejudice the outcomes. However, there are examples where individual participants have changed their minds on issues but this has normally occurred as a consequence of a useful discussion.
Notwithstanding, the focus group process elicited a range of data that offers rich insights into how these groups of people viewed the several issues that were raised. There are several themes that have been identified from the data and these will be more fully discussed in Chapter 8 along with the discussion that will follow the presentation of the quantitative part of the study in Chapter 7.
Chapter 7
Community Participation Through a Survey Questionnaire

7.1 Introduction
This chapter presents the results of the second part of this research study. The approach taken in this quantitative study was to survey members of the Geelong community using a telephone technique. Telephone contacts have the benefit of being timely and cost efficient.

Smith, Mitchell, Attebo, and Leeder (1997) have reported on selection bias that may occur with telephone sampling but nominate the major persons excluded as those that are younger, non-home owners or not born in Australia. The sample selected for this study has dealt with the age issue but the other characteristics need to be recognised as potential issues in any generalisation of results to the wider community that might be undertaken. Wilson, Starr, Taylor, and Dal Grande (1999) have chosen to accept the principle of telephone surveying and have sought to compare two telephone survey methods. The use of electronic white pages as the sampling frame was compared to random digit dialling with the conclusion being that the former method offers no significant deterioration in sampling bias. Further the research indicates substantial methodological and cost advantages in using the electronic white pages.

This part of the research has adopted the telephone technique, primarily because it was cost effective and could be undertaken over a relatively short time frame. The larger issue when considering the results is not so much any sampling bias that may have been generated by using this method, but the variability in response rates that was experienced throughout the survey period.

This chapter details the community survey undertaken over an eight-week period commencing in June 2000. It considers the sample and methodology used, including the participants, the procedures taken, the interview schedule and the data analysis. The major part of the chapter presents the results.
From time to time, emerging trends are identified that aim to draw out particular points from the section being presented. These comments will be in a different typeface (Comic Sans MS).

7.2 The Sample and Methodology

7.2.1 Ethical approval
The Research and Ethics Advisory Committee of Barwon Health (REAC) approved this part of the research study. Full approval was granted on 16 May 2000 under Study 99/71 E1 (refer Appendix D). A Final Report was submitted to REAC on 23 November 2000.

The study was also approved by Deakin University Ethics Committee (DUEC) subject to evidence of clearance from Barwon Health. This was provided to DUEC and full approval was granted for the period from 11 April 2000 to 31 December 2000 under Study EC 48-2000 (refer Appendix E). A Final Report was submitted to DUEC on 20 December 2000.

7.2.2 The participants
The sample comprised 400 Geelong residents. A stratified random sample was used which was stratified by gender, age, and socioeconomic status. Equal numbers of men and women were interviewed, an equal number of people aged 18 to 40 years and aged 41 years or over, and an equal number from suburbs of a lower and higher socioeconomic status (SES). The sample size was based on the number of independent variables considered (sex, age, and SES), and the number of levels within each (2 X 2 X 2). Given these factors, there were 8 cells or subgroups in the data set. For example, one cell represented people with a lower SES, who are older, who are males. In order to make some meaningful comments about the views of each subgroup, 50 participants in each subgroup were interviewed. Interviewers were given log sheets with numbers for either the upper or the lower SES suburbs, and were assigned an age or sex group to interview.

Telephone numbers were randomly selected from the Geelong residential telephone directory, using the program Australia On Disk, May 2000 version. Half of the randomly
selected numbers were sourced from several suburbs of a lower SES, and half from several suburbs of a higher SES. Telephone numbers were copied to log sheets on which the telephone interviewers recorded information about every contact or attempted contact with each telephone number.

Suburbs were differentiated into higher or lower SES through an analysis of the Australian Bureau of Statistics 1996 census data for statistical local areas in the Greater Geelong City Part A statistical subdivision (Australian Bureau of Statistics, 2000). Median individual and household income were used as markers for the SES of the suburbs within each statistical local area. These are presented in Table 7.1.

Table 7.1 1996 Census of Population and Housing – Basic Community Profiles Greater Geelong City Part A (Statistical Subdivision)

<table>
<thead>
<tr>
<th>Statistical Local Area</th>
<th>Median individual income</th>
<th>Median household income</th>
<th>Socioeconomic suburbs*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Geelong (Newcomb)</td>
<td>242</td>
<td>496</td>
<td>Lower</td>
</tr>
<tr>
<td>Corio – Inner (e.g. Corio, Norlane)</td>
<td>218</td>
<td>542</td>
<td>Lower</td>
</tr>
<tr>
<td>Newtown</td>
<td>302</td>
<td>615</td>
<td>Higher</td>
</tr>
<tr>
<td>South Barwon (e.g. Highton, Grovedale)</td>
<td>272</td>
<td>638</td>
<td>Higher</td>
</tr>
</tbody>
</table>

* This denotes the designation applied by the researcher

Note: Income figures are weekly income, expressed in $AUS.
Source: Australian Bureau of Statistics, 2000

Contact was made with a total of 2,178 households. Of these, there was no person of the appropriate age or sex in 646 households, and in 60 households the person did not speak English sufficiently well to be interviewed. A total of 940 individuals who were invited to be interviewed refused, and 88 people refused on behalf of another person. Interviewing continued until 400 interviews were completed. A further 44 people were listed as call
backs and may have completed the interview. However, either an interviewer was unavailable at the time nominated for a call back or there was no longer a requirement for people of that age, sex and SES category when the call back was due. Of the 1384 eligible people directly contacted, 940 refused to be interviewed, and 444 were either interviewed and could have been interviewed but were not, giving a consent rate of 32%. If the individuals who were potential callbacks are excluded, of the 1340 eligible people directly contacted, 400 were interviewed, giving a consent rate of 30%. Using the latter criteria, the response rate for the upper SES suburbs was 43%, and 23% for the lower SES suburbs.

The sex, age, highest level of formal education completed, and the employment status of participants are presented in Table 7.2 (next page). This information is compared to the 1996 Census data from the Australian Bureau of Statistics, adapted to ensure a consistent approach.

There were 240 (60%) participants who were married, 19 (5%) de facto, 27 (7%) widowed, 27 (7%) divorced, 11 (3%) separated but not divorced, 71 (17%) never married, and 5 (1%) would not answer this question. Over three-quarters had children (n = 307, 77%), 92 (23%) indicated they did not have children, and one participant would not answer this question.

Most participants reported their country of birth as Australia (n = 327, 82%), with 43 (11%) born outside of Australia in an English-speaking country, and 30 (7%) born in a non-English-speaking country. Almost all participants reported that the language they speak at home is English (n = 386, 97%).

Half of the participants (n = 200, 50%) came from a postcode representing the upper SES suburbs, while the remaining half came from several suburbs of a lower SES.

When asked if they do, or have ever, worked as a health professional, 56 (14%) stated that they had or do.
Table 7.2  Demographic Characteristics of the Sample and for all of Australia (Aged 18 years and Over)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Sample No. (%)</th>
<th>Census Data For all of Australia (%)*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>200 (50%)</td>
<td>6,431,470 (48.9%)</td>
</tr>
<tr>
<td>Female</td>
<td>200 (50%)</td>
<td>6,732,428 (51.1%)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18 to 30 years</td>
<td>83 (20.7%)</td>
<td>3,443,530 (26.2%)</td>
</tr>
<tr>
<td>31 to 40 years</td>
<td>117 (29.2%)</td>
<td>2,810,795 (21.4%)</td>
</tr>
<tr>
<td>41 to 50 years</td>
<td>61 (15.2%)</td>
<td>2,514,166 (19.1%)</td>
</tr>
<tr>
<td>51 to 60 years</td>
<td>39 (9.8%)</td>
<td>1,708,634 (13.0%)</td>
</tr>
<tr>
<td>61 to 70 years</td>
<td>58 (14.5%)</td>
<td>1,336,047 (10.1%)</td>
</tr>
<tr>
<td>71 to 79 years</td>
<td>33 (8.2%)</td>
<td>873,741 (6.6%)</td>
</tr>
<tr>
<td>80 years or more</td>
<td>9 (2.2%)</td>
<td>476,985 (3.6%)</td>
</tr>
<tr>
<td><strong>Education level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Higher degree</td>
<td>9 (2.2%)</td>
<td>190,840 (1.4%)</td>
</tr>
<tr>
<td>Tertiary diploma / degree</td>
<td>85 (21.2%)</td>
<td>2,106,565 (16.0%)</td>
</tr>
<tr>
<td>Vocational qualification</td>
<td>36 (9%)</td>
<td>1,881,744 (14.3%)</td>
</tr>
<tr>
<td>Completed Yr 12 or equiv</td>
<td>76 (19%)</td>
<td>N/A</td>
</tr>
<tr>
<td>Some secondary</td>
<td>179 (44.7%)</td>
<td>N/A</td>
</tr>
<tr>
<td>Primary only</td>
<td>15 (3.7%)</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed full time</td>
<td>110 (27.5%)</td>
<td>5,180,227 (36.9%)</td>
</tr>
<tr>
<td>Employed part time / cas.</td>
<td>71 (17.8%)</td>
<td>2,286,662 (16.3%)</td>
</tr>
<tr>
<td>Unemployed, seeking work</td>
<td>27 (6.8%)</td>
<td>771,970 (5.5%)</td>
</tr>
<tr>
<td>Home duties</td>
<td>57 (14.3%)</td>
<td>N/A</td>
</tr>
<tr>
<td>Retired</td>
<td>93 (23.2%)</td>
<td>N/A</td>
</tr>
<tr>
<td>Disability pension</td>
<td>24 (6%)</td>
<td>N/A</td>
</tr>
<tr>
<td>Student</td>
<td>13 (3.2%)</td>
<td>N/A</td>
</tr>
<tr>
<td>Other</td>
<td>5 (1.3%)</td>
<td>N/A</td>
</tr>
</tbody>
</table>

* Based on persons aged 18 years and over

** National data based on persons aged 15 years and over

Source: Australian Bureau of Statistics, 2000
Table 7.2 demonstrates how the sample for this study differs from the Australian demographic characteristics. Care has been taken to ensure comparisons are valid but the education level data provided nationally are for persons aged 15 years and over. However, given that the sample is for persons 18 years and over, the only line of data that should not be relied upon is the vocational qualification. Certain other parts of the National data are not available in a form that can be compared and these data have been noted as not available (N/A).

The gender profiles are similar for both the sample and the National data. The age profiles differ in that the sample under represents those aged 18 to 30 years, 41 to 60 years, and over represents 31 to 40 years and 61 to 80 years. This indicates the willingness and availability of persons wishing to participate in the survey.

Members of the community interviewed were more likely to be educated at a tertiary level although they may have been less likely to hold a vocational qualification. Certainly the number in full-time employment was fewer than would be expected for the total population.

7.2.3 The procedures taken

Prior to the commencement of interviewing, an experienced researcher trained the six interviewers involved in this study. An interviewer dialled each selected telephone number and, when a person answered, introduced her or himself as a researcher for Barwon Health and Deakin University and asked if there was a person of the appropriate age and gender living there. Where there was an appropriate person, the interviewer briefly explained the study and what it would involve for the potential participant, and asked if that person would consent to be interviewed. It was explained to potential participants that their responses would be confidential, that no identifying information would be stored with their responses, and that the interview would take approximately 20 minutes. Where there was no answer or an answering machine was used, that telephone number was tried a total of three times with at least one time being a weekday evening or a weekend to maximise the opportunity of contact with each selected household.
Each interview took approximately 20 minutes to complete. The telephone interviews were conducted between June 20th and August 15th 2000. At the conclusion of each interview, the interviewer offered the participant a summary of the main findings of the study. Where a participant requested a summary, the interviewer wrote the participant's name and address directly onto an envelope, which was kept separately to their responses. A total of 271 participants (68%) requested the summary, which was mailed to them on 6 November, 2000 (refer Appendix F).

7.2.4 The interview schedule
A highly structured interview schedule was utilised. The 62 questions included a number of open questions with pre-coded response categories for the interviewers' use. A complete copy of the interview schedule is found at Appendix G. The interview began with a number of open questions which asked participants some general questions about the public health care system, for example what do they value about the health system, what are the shortfalls, and where should more money be spent. These open questions were deliberately placed at the beginning of the interview, before any specific services were mentioned, in order to elicit the aspects of the public health care system, which were most salient to participants. Open-ended questions enabled respondents to give one or more responses, hence some percentages in this report total in excess of 100.

Two series of questions asked participants to rate a number of specific health services using an 11-point rating scale ranging from “Poor” to “Excellent” or from “Not at all important” to “Extremely important”. Other items presented participants with several possible responses from which they selected one. These items included a series of questions in which participants were asked if it was more important to spend money in one area or an alternative area. A number of problems in the public health care system, identified by participants in the focus group discussions which were conducted in the first part of this study, were included in the interview schedule. Participants were asked to rate each as a “Serious problem”, “Mild problem” or “Not a problem”. Participants were read a number of statements with fixed responses comprising 5-point Likert scales ranging from “Strongly agree” to “Strongly disagree”. Demographic information was also collected.
Several versions of the interview schedule were used. The order of questions within sections was varied where possible, and where two options were presented the order of presentation was counter-balanced to control for order effects.

The interview schedule was tested in telephone interviews with ten individuals. Three of these were experienced in research, the other seven were not. The wording on some items was altered to improve the clarity of some questions, and the order of some items was changed to improve the flow of the interview. None of the individuals found the questions too difficult or intrusive.

7.2.5 Data analysis

The Statistical Package for the Social Sciences (SPSS) Version 8 was used for data analysis. In the majority of questions where participants were given a range of responses and asked to select one, respondents who could not answer are presented as “Can’t say” in the results. Where the response categories ranged from “Strongly agree” to “Strongly disagree”, participants who could not answer were coded as “Neither agree nor disagree”.

A series of chi-square and independent samples t-test analyses was conducted comparing men and women, participants aged 18 to 40 with those aged over 40, and participants living in upper SES suburbs with those living in lower SES suburbs. A brief summary of the findings of these analyses is included with each section of the descriptive data. Appendix H presents the findings from each of these analyses in table form. Comparisons were undertaken for responses to open questions only where 10% or more of participants responded.

7.3 The Results

The study aimed to elicit opinion on the key components of the public health care system that form the basis of this thesis. The descriptive data are reported under the following broad headings:

- Priorities
7.3.1 Priorities

7.3.1.1 What services are most important?
An open question was used to identify the services that participants think are most important for the public health care system to provide. Responses are listed in Table 7.3.

Comparisons
Men were more likely than women to mention hospitals or more beds as most important. Participants from the higher SES suburbs were less likely than those from the lower SES suburbs to mention hospitals or more beds and shorter waiting times as being the most important services for the public health care system to provide.

7.3.1.2 Where should money be spent?
An open question was used asking participants if more money was available, where they think it should be spent. Responses are listed in Table 7.3 (next page).

Comparisons
Men were more likely than women to mention hospitals or more beds as areas where more money should be spent. Participants from the higher SES suburbs were less likely than those from the lower SES suburbs to mention shorter waiting times as where more money should be spent.

7.3.1.3 Emerging trends
These questions confirmed the view of the focus groups that hospital inpatient facilities, emergency services and aged care services were priority areas. There was a very strong response in favour of spending more resources in hospitals but not in
<table>
<thead>
<tr>
<th>Service / Area</th>
<th>Most important to provide No. (%)</th>
<th>Where spend more money No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospitals / More beds</td>
<td>113 (28%)</td>
<td>167 (42%)</td>
</tr>
<tr>
<td>Emergency services</td>
<td>75 (19%)</td>
<td>31 (8%)</td>
</tr>
<tr>
<td>Aged care</td>
<td>61 (15%)</td>
<td>66 (17%)</td>
</tr>
<tr>
<td>Doctors / More doctors</td>
<td>46 (12%)</td>
<td>20 (5%)</td>
</tr>
<tr>
<td>Shorter waiting times</td>
<td>38 (10%)</td>
<td>46 (12%)</td>
</tr>
<tr>
<td>Dental services</td>
<td>37 (9%)</td>
<td>24 (6%)</td>
</tr>
<tr>
<td>Maternal / child health</td>
<td>31 (8%)</td>
<td>21 (5%)</td>
</tr>
<tr>
<td>Nothing / No response</td>
<td>28 (7%)</td>
<td>28 (7%)</td>
</tr>
<tr>
<td>Everything is important</td>
<td>27 (7%)</td>
<td>10 (3%)</td>
</tr>
<tr>
<td>More staff</td>
<td>23 (6%)</td>
<td>82 (21%)</td>
</tr>
<tr>
<td>Elective surgery</td>
<td>21 (5%)</td>
<td>15 (4%)</td>
</tr>
<tr>
<td>Mental health services</td>
<td>21 (5%)</td>
<td>16 (4%)</td>
</tr>
<tr>
<td>Free health care</td>
<td>18 (5%)</td>
<td>4 (1%)</td>
</tr>
<tr>
<td>Ambulances</td>
<td>16 (4%)</td>
<td>7 (2%)</td>
</tr>
<tr>
<td>Education</td>
<td>13 (3%)</td>
<td>9 (2%)</td>
</tr>
<tr>
<td>Cheap / free medication</td>
<td>12 (3%)</td>
<td>4 (1%)</td>
</tr>
<tr>
<td>Good quality care / service</td>
<td>11 (3%)</td>
<td>-</td>
</tr>
<tr>
<td>24 hour access to GPs</td>
<td>10 (3%)</td>
<td>-</td>
</tr>
<tr>
<td>Specialists / More specialists</td>
<td>10 (3%)</td>
<td>2 (.5%)</td>
</tr>
<tr>
<td>Home nursing</td>
<td>8 (2%)</td>
<td>5 (1%)</td>
</tr>
<tr>
<td>Vision / Hearing services</td>
<td>8 (2%)</td>
<td>2 (.5%)</td>
</tr>
<tr>
<td>Disability services</td>
<td>7 (2%)</td>
<td>8 (2%)</td>
</tr>
<tr>
<td>Hospice</td>
<td>7 (2%)</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>After care services</td>
<td>4 (1%)</td>
<td>-</td>
</tr>
<tr>
<td>Information</td>
<td>4 (1%)</td>
<td>-</td>
</tr>
<tr>
<td>Accessibility</td>
<td>4 (1%)</td>
<td>-</td>
</tr>
<tr>
<td>Children’s specialists</td>
<td>3 (1%)</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Outpatient services</td>
<td>3 (1%)</td>
<td>4 (1%)</td>
</tr>
</tbody>
</table>

(Cont.)
Table 7.3  Most Important Services and Where Should More Money be Spent (Cont.)

<table>
<thead>
<tr>
<th>Service / Area</th>
<th>Most important to provide No. (%)</th>
<th>Where spend more money No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research</td>
<td>3 (1%)</td>
<td>18 (5%)</td>
</tr>
<tr>
<td>Research – Cancer</td>
<td>3 (1%)</td>
<td>5 (1%)</td>
</tr>
<tr>
<td>Ancillary services</td>
<td>2 (0.5%)</td>
<td>2 (0.5%)</td>
</tr>
<tr>
<td>Community health centres</td>
<td>2 (0.5%)</td>
<td>-</td>
</tr>
<tr>
<td>Detox places / Drug and alcohol</td>
<td>2 (0.5%)</td>
<td>6 (2%)</td>
</tr>
<tr>
<td>Prevention</td>
<td>2 (0.5%)</td>
<td>2 (0.5%)</td>
</tr>
<tr>
<td>Screening tests</td>
<td>2 (0.5%)</td>
<td>1 (0.3%)</td>
</tr>
<tr>
<td>School nurses</td>
<td>2 (0.5%)</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Diagnostic tests</td>
<td>2 (0.5%)</td>
<td>-</td>
</tr>
<tr>
<td>Child care</td>
<td>2 (0.5%)</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Equipment</td>
<td>-</td>
<td>6 (2%)</td>
</tr>
<tr>
<td>Facilities</td>
<td>-</td>
<td>4 (1%)</td>
</tr>
<tr>
<td>Serious illness</td>
<td>-</td>
<td>4 (1%)</td>
</tr>
<tr>
<td>Rural health services</td>
<td>-</td>
<td>2 (0.5%)</td>
</tr>
<tr>
<td>Rehab</td>
<td>-</td>
<td>2 (0.5%)</td>
</tr>
<tr>
<td>No need to spend more money</td>
<td>-</td>
<td>2 (0.5%)</td>
</tr>
<tr>
<td>Other</td>
<td>13 (3%)</td>
<td>27 (7%)</td>
</tr>
</tbody>
</table>

emergency services. Support for spending more money in aged care reflected the priority it was given. While there was some support for having more doctors, this was not matched with a commitment to spend more money in this area. Shorter waiting times also reflected the priorities of the focus groups and resources were favoured to be directed into that area. This area takes an even higher priority when joined with the elective surgery responses, which could reasonably be viewed as a linked priority. Dental and maternal/child health services were seen as priorities but there was a reluctance to recognise these priorities in the allocation of money.
The employment of more staff was viewed as a lower priority but 82 participants considered more money should be spent in this area. This could be linked to the top priorities where the needs of acute services were clearly identified. The way to deal with this could be interpreted to be by employing more staff. By grouping the higher priority hospital based services together an interesting picture emerges.

<table>
<thead>
<tr>
<th>Most important to provide</th>
<th>Where to spend more money</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospitals/more beds</td>
<td>113 (28%)</td>
</tr>
<tr>
<td>Emergency services</td>
<td>75 (19%)</td>
</tr>
<tr>
<td>Doctors/more doctors</td>
<td>46 (12%)</td>
</tr>
<tr>
<td>Shorter waiting times</td>
<td>38 (10%)</td>
</tr>
<tr>
<td>More staff</td>
<td>23 (6%)</td>
</tr>
<tr>
<td>Elective surgery</td>
<td>21 (5%)</td>
</tr>
<tr>
<td>&quot;Hospital based&quot; services</td>
<td>316</td>
</tr>
<tr>
<td></td>
<td>167 (42%)</td>
</tr>
<tr>
<td></td>
<td>31 (8%)</td>
</tr>
<tr>
<td></td>
<td>20 (5%)</td>
</tr>
<tr>
<td></td>
<td>46 (12%)</td>
</tr>
<tr>
<td></td>
<td>82 (21%)</td>
</tr>
<tr>
<td></td>
<td>15 (4%)</td>
</tr>
<tr>
<td></td>
<td>361</td>
</tr>
</tbody>
</table>

There were 694 responses identified as the most important services and 664 areas were nominated to receive money. The hospital based services therefore represented 45.5% of the services most important to provide and 54.4% of the areas where money should be spent.

Overall, the data show a strong awareness of the needs of the acute and aged care sectors with little recognition of those services provided in a non-institutional setting. When asked where money should be spent, preferences were generally towards the same acute and aged care sectors. The one exception was a modest increase in interest towards putting money into research although this area was not identified greatly as of much importance.
7.3.1.4 Rating the importance of various services

Participants were asked to rate the importance of various services on a scale from 0 to 10, with 0 being "Not at all important", and 10 being "Extremely important". The number of participants who rated each service, and the range, mean, and standard deviation (SD) for each service are presented in Table 7.4. Some participants indicated that they could not provide a rating for some services.

Table 7.4  Rating the Importance of Services

<table>
<thead>
<tr>
<th>Service</th>
<th>n</th>
<th>Range</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accident and emergency services</td>
<td>400</td>
<td>3 – 10</td>
<td>9.48</td>
<td>1.09</td>
</tr>
<tr>
<td>Special care and pain relief for the dying</td>
<td>397</td>
<td>2 – 10</td>
<td>9.04</td>
<td>1.35</td>
</tr>
<tr>
<td>Preventive screening and immunisations</td>
<td>398</td>
<td>3 – 10</td>
<td>9.00</td>
<td>1.28</td>
</tr>
<tr>
<td>Aged care services</td>
<td>397</td>
<td>2 – 10</td>
<td>8.86</td>
<td>1.36</td>
</tr>
<tr>
<td>Services for people with mental illness</td>
<td>393</td>
<td>0 – 10</td>
<td>8.79</td>
<td>1.54</td>
</tr>
<tr>
<td>Surgery such as hip replacement surgery</td>
<td>397</td>
<td>5 – 10</td>
<td>8.75</td>
<td>1.28</td>
</tr>
<tr>
<td>Hospital based services</td>
<td>398</td>
<td>1 – 10</td>
<td>8.69</td>
<td>1.46</td>
</tr>
<tr>
<td>After-care services for patients</td>
<td>400</td>
<td>0 – 10</td>
<td>8.32</td>
<td>1.65</td>
</tr>
<tr>
<td>Long stay hospital care for elderly people</td>
<td>392</td>
<td>2 – 10</td>
<td>8.27</td>
<td>1.81</td>
</tr>
<tr>
<td>Health education services</td>
<td>399</td>
<td>0 – 10</td>
<td>8.03</td>
<td>1.93</td>
</tr>
<tr>
<td>Drug and alcohol services</td>
<td>391</td>
<td>0 – 10</td>
<td>7.86</td>
<td>2.39</td>
</tr>
<tr>
<td>Free dental services</td>
<td>399</td>
<td>0 – 10</td>
<td>7.63</td>
<td>2.05</td>
</tr>
</tbody>
</table>

Comparisons

The mean rating of importance obtained by men was lower than that obtained by women for 9 of the 12 services rated (listed in Table 7.4). The only services where there was no significant difference in the mean rating scores obtained by men and women were accident
and emergency services; hospital based services; and long stay hospital care for elderly people.

Older participants obtained higher mean ratings of importance than younger participants for three services; after-care services for patients; health education services; and free dental services.

Participants in the upper SES suburbs obtained lower mean ratings of importance than those from lower SES suburbs for three services; preventive screening and immunisations; hospital based services; and free dental services.

Upper SES participants rated the importance of drug and alcohol services higher than participants from lower SES suburbs.

7.3.1.5 Emerging trends
The mean rankings for all services mentioned were in the upper ranges so all areas were seen to be of some to extreme importance. Clearly the critical areas of care are identified as most important but the strong showing of special care and pain relief for the dying indicates a keen awareness of the importance of palliative care. This was not a major outcome of the focus group study.

In relative terms, the non-acute areas of service ranked ahead of the traditional hospital based services including hip replacement surgery. Indeed, services for people with mental illness and aged care services were seen to be more important than the non-emergency hospital care.

Drug and alcohol services and free dental services rated relatively lower but their standard deviations suggest that there was quite a wide spread of views on these services.
7.3.1.6 Should additional funds be spent on particular services?
Participants were asked if they agree or disagree with a number of statements. “Strongly Agree” was scored as 5, “Strongly Disagree” as 1. The results are presented in Table 7.5 (next page).

7.3.1.7 Where should additional money come from?
Participants who agreed that a number of services should receive more funding were asked where they thought the additional funds should come from. Responses to an open question asking where the extra money should come from are listed in Table 7.6 (p. 126). Fifty-four (14%) of these participants did not know where the additional money should come from. Other responses from individual participants fell into one of three categories. These were to:

- reduce Government expenditure;
- identify alternative sources of funding; or
- reduce other health services.

Comparisons.
There were few differences between groups in response to these items. Men were less likely than women to agree that there should be more men’s health services available, and upper SES participants were less likely than lower SES participants to suggest raising taxes for everyone as a way of raising additional money.

7.3.1.8 Emerging trends
Table 7.5 measures the level of agreement with eight different propositions. Six of the propositions give a relative assessment of agreement and priority with the final two propositions indicating support for services in negatively angled questions.

The responses indicated a strong preference in favour of additional funding for nurses with health education in schools being the next priority. Mental health and suicide prevention also rated positively.
<table>
<thead>
<tr>
<th>Statement</th>
<th>Mean</th>
<th>SD</th>
<th>Strongly Agree No. (%)</th>
<th>Agree No. (%)</th>
<th>Neither Ag / Dis No. (%)</th>
<th>Disagree No. (%)</th>
<th>Strongly Disagree No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>More funds should be put into employing additional Nurses</td>
<td>4.28</td>
<td>.79</td>
<td>174 (44%)</td>
<td>185 (46%)</td>
<td>21 (5%)</td>
<td>19 (5%)</td>
<td>1 (0%)</td>
</tr>
<tr>
<td>There should be more health education in schools</td>
<td>4.00</td>
<td>.98</td>
<td>135 (34%)</td>
<td>183 (46%)</td>
<td>34 (8%)</td>
<td>44 (11%)</td>
<td>4 (1%)</td>
</tr>
<tr>
<td>More funds should be put into mental health</td>
<td>3.80</td>
<td>.91</td>
<td>84 (21%)</td>
<td>199 (50%)</td>
<td>72 (18%)</td>
<td>43 (10%)</td>
<td>2 (1%)</td>
</tr>
<tr>
<td>More funds should be put into suicide prevention</td>
<td>3.70</td>
<td>1.07</td>
<td>94 (24%)</td>
<td>176 (44%)</td>
<td>56 (14%)</td>
<td>64 (16%)</td>
<td>10 (2%)</td>
</tr>
<tr>
<td>There should be more men's health services available</td>
<td>3.54</td>
<td>.94</td>
<td>52 (13%)</td>
<td>183 (46%)</td>
<td>96 (24%)</td>
<td>66 (16%)</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>If more money was spent on CBS, fewer people would need to go to hospital</td>
<td>3.49</td>
<td>1.08</td>
<td>65 (16%)</td>
<td>178 (45%)</td>
<td>54 (13%)</td>
<td>95 (24%)</td>
<td>8 (2%)</td>
</tr>
<tr>
<td>There are enough services in the Geelong area to help people get off drugs or alcohol</td>
<td>2.61</td>
<td>1.02</td>
<td>14 (3%)</td>
<td>57 (14%)</td>
<td>150 (38%)</td>
<td>117 (29%)</td>
<td>62 (16%)</td>
</tr>
<tr>
<td>Spending money on health education is a waste of money</td>
<td>2.01</td>
<td>.98</td>
<td>6 (1%)</td>
<td>45 (11%)</td>
<td>21 (5%)</td>
<td>202 (51%)</td>
<td>126 (32%)</td>
</tr>
</tbody>
</table>
Table 7.6  Where Participants Suggested Extra Money Should Come From

<table>
<thead>
<tr>
<th>Where extra money should come from</th>
<th>No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase taxes for everyone</td>
<td>63 (16%)</td>
</tr>
<tr>
<td>Cut politician's pay, travelling, perks</td>
<td>51 (13%)</td>
</tr>
<tr>
<td>Increase taxes – wealthy only</td>
<td>28 (7%)</td>
</tr>
<tr>
<td>From gambling revenue</td>
<td>25 (6%)</td>
</tr>
<tr>
<td>From GST revenue / advertisements</td>
<td>22 (6%)</td>
</tr>
<tr>
<td>Increase Medicare levy for everyone</td>
<td>21 (5%)</td>
</tr>
<tr>
<td>From the Government</td>
<td>16 (4%)</td>
</tr>
<tr>
<td>Petrol / road tax</td>
<td>16 (4%)</td>
</tr>
<tr>
<td>Cut spending – various areas</td>
<td>13 (3%)</td>
</tr>
<tr>
<td>Fundraising / donations</td>
<td>13 (3%)</td>
</tr>
<tr>
<td>Tax on alcohol / cigarettes</td>
<td>13 (3%)</td>
</tr>
<tr>
<td>Other sources</td>
<td>12 (3%)</td>
</tr>
<tr>
<td>Big business / corporations contribute</td>
<td>11 (3%)</td>
</tr>
<tr>
<td>Cut spending on sports / Olympics</td>
<td>11 (3%)</td>
</tr>
<tr>
<td>Increase Medicare levy – wealthy only</td>
<td>11 (3%)</td>
</tr>
<tr>
<td>Cut defence spending</td>
<td>10 (3%)</td>
</tr>
<tr>
<td>Redistribute funds</td>
<td>9 (2%)</td>
</tr>
<tr>
<td>Streamline / improve efficiency</td>
<td>7 (2%)</td>
</tr>
<tr>
<td>Cut other health services – nothing specific</td>
<td>7 (2%)</td>
</tr>
<tr>
<td>Special levy</td>
<td>6 (2%)</td>
</tr>
<tr>
<td>Cut administrators’ salaries / admin. costs</td>
<td>6 (2%)</td>
</tr>
<tr>
<td>More private health insurance</td>
<td>5 (1%)</td>
</tr>
<tr>
<td>Reduce drug dependency services</td>
<td>4 (1%)</td>
</tr>
<tr>
<td>Cut foreign aid</td>
<td>4 (1%)</td>
</tr>
<tr>
<td>Cut funding to useless things</td>
<td>4 (1%)</td>
</tr>
<tr>
<td>Most, or people who can, pay something</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Reduce other health services</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Cut welfare spending</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Cut council rates</td>
<td>2 (0.5%)</td>
</tr>
<tr>
<td>Cut spending in non-health areas</td>
<td>2 (0.5%)</td>
</tr>
<tr>
<td>Cut funding for aboriginalals</td>
<td>2 (0.5%)</td>
</tr>
</tbody>
</table>
The issue of drugs and alcohol showed up a relative lack of concern for extra funds in this area with only 45% responding in favour of more resources. Health education, on the other hand, had the positive support of 83% of participants for extra funds. These latter questions confirmed that participants could discriminate their responses according to the question and were giving thought to the issues raised.

In Table 7.6, the 400 participants identified 32 sources of funds from the 455 ideas coming from them. The most common response was to increase taxation. Of all the suggestions, nine related to revenue increases to Government. These included:

<table>
<thead>
<tr>
<th>Source</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase taxes for everyone</td>
<td>63 (16%)</td>
</tr>
<tr>
<td>Increase taxes - wealthy</td>
<td>28 (7%)</td>
</tr>
<tr>
<td>Gambling revenue</td>
<td>25 (6%)</td>
</tr>
<tr>
<td>GST revenue/advertisements</td>
<td>22 (6%)</td>
</tr>
<tr>
<td>Increase Medicare levy</td>
<td>21 (5%)</td>
</tr>
<tr>
<td>Petrol/road tax</td>
<td>16 (4%)</td>
</tr>
<tr>
<td>Tax on alcohol/cigarettes</td>
<td>13 (3%)</td>
</tr>
<tr>
<td>Increase Medicare levy - wealthy</td>
<td>11 (3%)</td>
</tr>
<tr>
<td>Special levy</td>
<td>6 (2%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>205</strong></td>
</tr>
</tbody>
</table>

This means that 205 of the 455 ideas were proposing some form of additional revenue from Government.

**7.3.1.9 Funding alternatives**

Participants were asked which of two services it is more important to spend money on. These questions forced participants to choose between two alternatives. A number of participants indicated that they could not choose. Responses are listed in Table 7.7.
Table 7.7  Responses to Funding Alternatives Questions

<table>
<thead>
<tr>
<th>Alternatives presented</th>
<th>No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community based services (CBS) OR</td>
<td>63 (16%)</td>
</tr>
<tr>
<td>Hospitals</td>
<td>242 (60%)</td>
</tr>
<tr>
<td>Can’t say</td>
<td>95 (24%)</td>
</tr>
<tr>
<td>Curing illness OR</td>
<td>150 (37%)</td>
</tr>
<tr>
<td>Educating the public about health risks</td>
<td>147 (37%)</td>
</tr>
<tr>
<td>Can’t say</td>
<td>103 (26%)</td>
</tr>
<tr>
<td>Cancer research OR</td>
<td>287 (72%)</td>
</tr>
<tr>
<td>Intensive care units for people over 80</td>
<td>30 (7%)</td>
</tr>
<tr>
<td>Can’t say</td>
<td>83 (21%)</td>
</tr>
<tr>
<td>Saving a mother who needs lots of care OR</td>
<td>199 (50%)</td>
</tr>
<tr>
<td>Saving a premature baby - needs lots of care</td>
<td>36 (9%)</td>
</tr>
<tr>
<td>Can’t say</td>
<td>165 (41%)</td>
</tr>
</tbody>
</table>

Comparisons.

Men were more likely than women to choose hospitals over community based services. Older participants were more likely than younger participants to select saving the mother rather than saving the premature baby. Participants from the upper SES suburbs were less likely than those from lower SES suburbs to choose hospitals over community based services, and to choose curing illness over educating the public about health risks.

7.3.1.10 Emerging trends

The emphasis on the public hospital system is evident in the first of these alternative questions. The relatively low commitment to CBS accords with the low priority accorded to it in other questions in the survey (refer to tables 7.3 and 7.4).
The highest consensus view in these data is where there is a choice between cancer research and intensive care units for people over 80 years. The majority view was to support cancer research and this is consistent with the outcome of the focus group data as presented in the previous chapter.

The other two questions are quite vexing as it would seem that many participants were reluctant to make the hard choices between the options given. A total of 165 participants were unable to make a choice between the mother or the baby. However, of those that were prepared to make a choice, an overwhelming number opted to treat the mother.

7.3.2 Expectations

7.3.2.1 How well are needs met?

Participants were asked how well the public health care system meets their needs with the following results:

- extremely well 36 (9%)
- very well 113 (28%)
- quite well 154 (38%)
- not very well 42 (11%)
- not at all 15 (4%)
- could not say 40 (10%)

Comparisons

There were no differences across groups in the proportion of participants who responded either “Extremely well” or “Very well”.

7.3.2.2 Shortfalls in the public health care system

An open question was used to ask participants to identify the shortfalls in the public health care system. Table 7.8 presents the frequency of each response to this question.
Table 7.8  Shortfalls in the Public Health Care System

<table>
<thead>
<tr>
<th>Shortfall</th>
<th>No. (%)</th>
<th>Shortfall</th>
<th>No (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Waiting (elect. surgery)</td>
<td>136 (34%)</td>
<td>Disabilities services</td>
<td>5 (1%)</td>
</tr>
<tr>
<td>Waiting (in general)</td>
<td>58 (15%)</td>
<td>Aged care services</td>
<td>5 (1%)</td>
</tr>
<tr>
<td>Staff shortages</td>
<td>59 (15%)</td>
<td>Interns in emergency</td>
<td>5 (1%)</td>
</tr>
<tr>
<td>Nothing / no response</td>
<td>59 (15%)</td>
<td>Doctors too quick</td>
<td>4 (1%)</td>
</tr>
<tr>
<td>Waiting (emergency)</td>
<td>50 (13%)</td>
<td>Lack of information</td>
<td>4 (1%)</td>
</tr>
<tr>
<td>Waiting (specialist)</td>
<td>47 (12%)</td>
<td>Too many changes</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Funding shortages</td>
<td>42 (11%)</td>
<td>Lack of co-ordination</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Waiting (GPs)</td>
<td>41 (10%)</td>
<td>Nurses treat pats. poorly</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Beds closing</td>
<td>39 (10%)</td>
<td>Early discharge</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Staff overworked</td>
<td>22 (6%)</td>
<td>Not enough detox</td>
<td>2 (0.5%)</td>
</tr>
<tr>
<td>Gap rich and poor</td>
<td>20 (5%)</td>
<td>Over-use of system</td>
<td>2 (0.5%)</td>
</tr>
<tr>
<td>Waiting (dental)</td>
<td>18 (5%)</td>
<td>Hospital not clean</td>
<td>2 (0.5%)</td>
</tr>
<tr>
<td>Dental services</td>
<td>15 (4%)</td>
<td>Accessibility</td>
<td>2 (0.5%)</td>
</tr>
<tr>
<td>Cost</td>
<td>13 (3%)</td>
<td>Too many admin' ters.</td>
<td>2 (0.5%)</td>
</tr>
<tr>
<td>Nurses overworked</td>
<td>12 (3%)</td>
<td>Infections in hospital</td>
<td>2 (0.5%)</td>
</tr>
<tr>
<td>Mental health services</td>
<td>8 (2%)</td>
<td>Outpatients services</td>
<td>2 (0.5%)</td>
</tr>
<tr>
<td>Lack of choice</td>
<td>7 (2%)</td>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

Comparisons
Participants from the upper SES suburbs were less likely to mention waiting for elective surgery or waiting for a specialist as a shortfall.

7.3.2.3 Emerging trends
The data suggest major concerns in relation to waiting times, not only for public hospital services but also for consulting specialists and general practitioners. This may reflect personal experiences. It may also be a response to the widespread media attention that was being given at the time of the survey to the problems of waiting at public hospitals. Issues of staff shortages, staff being overworked and beds closing
may be a similar story. There is a high degree of similarity in the themes of the responses given to this question.

7.3.2.4 Rating specific problems
Participants were read a list of things that some people have had a problem with in the health system in the past and were asked to say if they think each one is a problem. They were asked if each one is a “serious problem”, a “mild problem”, or “not a problem”. Table 7.9 (next page) provides the number and percentage of participants giving each response for each problem, and the number who stated that they could not say. Participants responding “Can’t say” were excluded when calculating the means and SDs. “Serious problem” was scored at 3, “Not a problem” as 1.

Comparisons
There was only one significant difference between groups for these items. Older participants obtained a higher mean score than younger participants when rating needing an interpreter and not being offered one as a problem.

7.3.2.5 Rating the quality of various services
Participants were asked to rate various services on a scale from 0 to 10, with 0 being “Poor”, and 10 being “Excellent”. The number of participants who rated each service, and the range, mean, and SD for each service are presented in Table 7.10 (p. 133). Some participants indicated that they could not provide a rating for some services.

Comparisons.
Men compared with women, and older participants compared with younger participants, obtained higher mean ratings for The Geelong Hospital.

7.3.2.6 Emerging trends
All services were seen as important with all means being above the mid point of the scale. Grace McKellar Centre and The Geelong Hospital each scored very well.
<table>
<thead>
<tr>
<th>Problem</th>
<th>n</th>
<th>Mean</th>
<th>SD</th>
<th>Serious Problem No. (%)</th>
<th>Mild Problem No. (%)</th>
<th>Not a Problem No. (%)</th>
<th>Can't say No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having to wait too long for treatment</td>
<td>390</td>
<td>2.72</td>
<td>.51</td>
<td>291 (73%)</td>
<td>88 (22%)</td>
<td>11 (3%)</td>
<td>10 (2%)</td>
</tr>
<tr>
<td>Staff are too busy</td>
<td>391</td>
<td>2.68</td>
<td>.57</td>
<td>285 (72%)</td>
<td>85 (21%)</td>
<td>21 (5%)</td>
<td>9 (2%)</td>
</tr>
<tr>
<td>Being discharged from hospital too early</td>
<td>384</td>
<td>2.64</td>
<td>.59</td>
<td>270 (67%)</td>
<td>91 (23%)</td>
<td>23 (6%)</td>
<td>16 (4%)</td>
</tr>
<tr>
<td>Having to wait too long to get an appointment</td>
<td>387</td>
<td>2.47</td>
<td>.61</td>
<td>206 (52%)</td>
<td>157 (39%)</td>
<td>24 (6%)</td>
<td>13 (3%)</td>
</tr>
<tr>
<td>Needing an interpreter and not being offered one</td>
<td>317</td>
<td>2.33</td>
<td>.80</td>
<td>169 (42%)</td>
<td>83 (21%)</td>
<td>65 (16%)</td>
<td>83 (21%)</td>
</tr>
<tr>
<td>Not knowing what services are available</td>
<td>397</td>
<td>2.26</td>
<td>.68</td>
<td>157 (39%)</td>
<td>185 (46%)</td>
<td>55 (14%)</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Not enough after-care services for patients discharged from hospital</td>
<td>372</td>
<td>2.25</td>
<td>.73</td>
<td>157 (39%)</td>
<td>152 (38%)</td>
<td>63 (16%)</td>
<td>28 (7%)</td>
</tr>
</tbody>
</table>
Table 7.10  Rating Various Services from Poor to Excellent

<table>
<thead>
<tr>
<th>Service</th>
<th>n</th>
<th>Range</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grace McKellar Centre</td>
<td>230</td>
<td>2 - 10</td>
<td>7.57</td>
<td>1.73</td>
</tr>
<tr>
<td>The Geelong Hospital</td>
<td>371</td>
<td>0 - 10</td>
<td>7.43</td>
<td>1.94</td>
</tr>
<tr>
<td>Community based services in this area</td>
<td>322</td>
<td>0 - 10</td>
<td>6.86</td>
<td>1.82</td>
</tr>
<tr>
<td>Geelong’s public health care system</td>
<td>380</td>
<td>0 - 10</td>
<td>6.77</td>
<td>1.68</td>
</tr>
<tr>
<td>Victoria’s public health care system</td>
<td>320</td>
<td>2 - 10</td>
<td>5.69</td>
<td>1.60</td>
</tr>
</tbody>
</table>

7.3.2.7 Interactions with health professionals

Three questions related to how participants rated the social skills exhibited by health professionals during interactions with participants. These questions asked participants how often this happens. Participants responding “Can’t say” were excluded when calculating the means and SDs. “All of the Time” was scored as 4, “None of the Time” as 1. Responses are presented in Table 7.11 (next page).

7.3.2.8 Emerging trends

This question was particularly inserted as a consequence of the outcomes of the focus groups where many participants were critical of their doctor’s ability or willingness to communicate appropriately. These data do not totally support that proposition with the mean scores for each question indicating satisfaction all or most of the time for the majority of participants. However, almost one in four participants felt that doctors did not listen enough some or none of the time. A similar number did not believe specialists treated them with respect.
Table 7.11  
Interactions with Health Professionals

<table>
<thead>
<tr>
<th>Item</th>
<th>n</th>
<th>Mean</th>
<th>SD</th>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>None of the time</th>
<th>Can’t say</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does your doctor communicate with you clearly?</td>
<td>394</td>
<td>3.45</td>
<td>.73</td>
<td>228 (57%)</td>
<td>119 (30%)</td>
<td>42 (11%)</td>
<td>5 (1%)</td>
<td>6 (1%)</td>
</tr>
<tr>
<td>Do doctors listen enough to your problem?</td>
<td>396</td>
<td>3.13</td>
<td>.82</td>
<td>154 (29%)</td>
<td>148 (37%)</td>
<td>86 (21%)</td>
<td>8 (2%)</td>
<td>4 (1%)</td>
</tr>
<tr>
<td>Do specialists treat you with respect?</td>
<td>366</td>
<td>3.11</td>
<td>.89</td>
<td>151 (28%)</td>
<td>120 (30%)</td>
<td>80 (20%)</td>
<td>15 (4%)</td>
<td>34 (8%)</td>
</tr>
</tbody>
</table>

7.3.2.9 Responses to various attitudinal statements

Participants were asked if they agreed or disagreed with five statements relating to various aspects of health care. “Strongly Agree” was scored as 5, “Strongly Disagree” as 1. Responses are presented in Table 7.12 (next page).

Comparisons.

Men compared with women obtained a lower mean score, which indicates less agreement, for the statement “Patients who are able to understand should always have some say in decisions about their medical treatment”. Participants from the upper SES suburbs
obtained a higher mean score than those from the lower SES suburbs for that statement, and also for the statement “The patient’s quality of life should be considered in deciding whether to use lifesaving treatment or technology”.

Table 7.12  Responses to Various Attitudinal Statements about Health Care

<table>
<thead>
<tr>
<th>Statement</th>
<th>Mean</th>
<th>SD</th>
<th>Strongly Agree No. (%)</th>
<th>Agree No. (%)</th>
<th>Neither Ag / Dis No. (%)</th>
<th>Disagree No. (%)</th>
<th>Strongly Disagree No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients who are able to understand should always have some say in</td>
<td>4.42</td>
<td>0.75</td>
<td>210 (52%)</td>
<td>164 (41%)</td>
<td>11 (3%)</td>
<td>12 (3%)</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>decisions about their medical treatment.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The patient’s quality of life should be considered in deciding</td>
<td>4.19</td>
<td>0.91</td>
<td>169 (42%)</td>
<td>170 (43%)</td>
<td>34 (9%)</td>
<td>21 (5%)</td>
<td>6 (1%)</td>
</tr>
<tr>
<td>whether to use lifesaving treatment or technology.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>As a society, we need to learn to be more accepting of death.</td>
<td>4.13</td>
<td>0.78</td>
<td>128 (32%)</td>
<td>218 (55%)</td>
<td>33 (8%)</td>
<td>20 (5%)</td>
<td>1 (0%)</td>
</tr>
<tr>
<td>I know what health services are available in my area.</td>
<td>3.54</td>
<td>1.05</td>
<td>53 (13%)</td>
<td>218 (55%)</td>
<td>32 (8%)</td>
<td>87 (22%)</td>
<td>10 (2%)</td>
</tr>
<tr>
<td>When a person is extremely ill, and unlikely to live much longer no</td>
<td>3.02</td>
<td>1.28</td>
<td>51 (13%)</td>
<td>133 (33%)</td>
<td>36 (9%)</td>
<td>134 (34%)</td>
<td>46 (11%)</td>
</tr>
<tr>
<td>matter what treatment they have, doctors should always go ahead with</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>any treatment that is possible.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
7.3.2.10 Emerging trends

The majority of participants agreed or strongly agreed with all but the final statement. Opinion was almost equally divided as to whether or not doctors should press ahead with treatment, regardless of the likely outcome.

7.3.3 Values

7.3.3.1 What is valued most about the public health care system?

An open question asked participants what they value most about the public health care system. Responses are presented in Table 7.13.

Table 7.13  What is Valued about the Public Health Care System

<table>
<thead>
<tr>
<th>What value</th>
<th>No. (%)</th>
<th>What value</th>
<th>No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>It’s free / Medicare system</td>
<td>139 (35%)</td>
<td>It’s competent</td>
<td>6 (2%)</td>
</tr>
<tr>
<td>It’s there when needed</td>
<td>82 (21%)</td>
<td>Choose own doctor</td>
<td>4 (1%)</td>
</tr>
<tr>
<td>Nothing / No response</td>
<td>64 (16%)</td>
<td>Quick response</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Availability in Geelong</td>
<td>63 (16%)</td>
<td>Hospice service</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Available for everyone</td>
<td>48 (12%)</td>
<td>Grace McKellar</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Hospital / Geelong hospital</td>
<td>27 (7%)</td>
<td>Cancer care</td>
<td>2 (0.5%)</td>
</tr>
<tr>
<td>Quality service / staff</td>
<td>22 (6%)</td>
<td>Hospital in the home</td>
<td>2 (0.5%)</td>
</tr>
<tr>
<td>Negative comment</td>
<td>17 (4%)</td>
<td>Home nursing service</td>
<td>2 (0.5%)</td>
</tr>
<tr>
<td>Emergency care</td>
<td>13 (3%)</td>
<td>Dental service</td>
<td>2 (0.5%)</td>
</tr>
<tr>
<td>Aged care in general</td>
<td>8 (2%)</td>
<td>Other</td>
<td>14 (4%)</td>
</tr>
</tbody>
</table>

Comparisons

Men were more likely than women to mention being available for everyone as something that is valued. Older participants were more likely than younger participants to mention the fact that it is there when needed as something that is valued. Participants from the upper SES suburbs were less likely than those from the lower SES suburbs to mention the fact that it is free, and it is there when needed, and more likely to mention that it is available for everyone as something that is valued.
7.3.3.2 Emerging trends

These data emphasise the value that is placed on Medicare. The fact that the public hospital service is provided at no cost to the patient and is accessible for all is viewed very positively by a large number of participants.

7.3.3.3 Comparison of three characteristics relating to service provision

Participants were presented with three pairs of choices and asked which of each pair is most important to them. Responses are presented in Table 7.14.

Comparisons.

Men were less likely than women to choose either good quality service or getting the service quickly over getting the service for free. There were no significant differences between the two age groups. Participants from the upper SES suburbs were more likely than those from the lower SES suburbs to choose getting the service quickly over getting the service for free, and less likely to choose getting good quality service over getting the service quickly.

Table 7.14  Forced-Choice Comparisons of Three Characteristics Relating to Service Provision

<table>
<thead>
<tr>
<th>Options</th>
<th>No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting good quality service OR</td>
<td>338 (85%)</td>
</tr>
<tr>
<td>Getting the service for free</td>
<td>33 (8%)</td>
</tr>
<tr>
<td>Can’t say</td>
<td>29 (7%)</td>
</tr>
<tr>
<td>Getting the service quickly OR</td>
<td>291 (73%)</td>
</tr>
<tr>
<td>Getting the service for free</td>
<td>81 (20%)</td>
</tr>
<tr>
<td>Can’t say</td>
<td>28 (7%)</td>
</tr>
<tr>
<td>Getting the service quickly OR</td>
<td>92 (23%)</td>
</tr>
<tr>
<td>Getting good quality service</td>
<td>242 (61%)</td>
</tr>
<tr>
<td>Can’t say</td>
<td>66 (16%)</td>
</tr>
</tbody>
</table>
7.3.3.4 Emerging trends

This series of questions enables some conclusions to be reached about how the participants assign priorities between the three variables of quality, timeliness and cost. The majority of participants have placed quality ahead of timeliness and cost. A smaller majority place timeliness ahead of cost so it can be deduced that, for the majority of participants, a high quality, timely service takes precedence over the cost of that service. The data suggest that there is some variation between the higher and lower SES in relation to the impact of cost.

7.3.3.5 Reasons for making funding alternative decisions

When participants were asked which of two services was it more important to spend money on, they were asked “Why do you say that?” The reasons given provide information about participants’ values, and are listed in Tables 7.15 to 7.18 (p. 139 – 141).

Comparisons.

There were no significant differences between men and women, or between older and younger participants in the reasons given for making any of the funding alternative decisions. There were a number of differences between the two SES groups. Participants from the upper SES suburbs were more likely than those from the lower SES suburbs to comment that “Both are important” when choosing between hospitals or community based services, and between curing illness or educating the public. The upper SES participants were less likely to say people need hospitals when the illness is serious as a reason for choosing hospitals or community based services, and less likely to say you have to cure or treat people when choosing between curing illness and educating the public. The upper SES participants were also less likely to say that a mother could have other children later as a reason for choosing either the mother or the baby in the last funding alternative decision.

7.3.3.6 Emerging trends

These responses give some interesting insights into the reasons why participants took a particular decision. Table 7.15 affirms again the priority afforded to the public
### Table 7.15  Reasons Given for Choosing Community Based Services (CBS) or Hospitals

<table>
<thead>
<tr>
<th>Reasons given</th>
<th>No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>People need hospitals when illness is serious</td>
<td>117 (29%)</td>
</tr>
<tr>
<td>Hospitals need money now</td>
<td>101 (25%)</td>
</tr>
<tr>
<td>Both are important</td>
<td>88 (22%)</td>
</tr>
<tr>
<td>Everything people need is in hospital</td>
<td>38 (10%)</td>
</tr>
<tr>
<td>More CBS might reduce need for hospital</td>
<td>31 (8%)</td>
</tr>
<tr>
<td>CBS are first contact people have with health system</td>
<td>29 (7%)</td>
</tr>
<tr>
<td>CBS are more accessible</td>
<td>8 (2%)</td>
</tr>
<tr>
<td>More people need hospital</td>
<td>8 (2%)</td>
</tr>
<tr>
<td>CBS have range of services</td>
<td>5 (1%)</td>
</tr>
<tr>
<td>Hospital has emergency services</td>
<td>4 (1%)</td>
</tr>
<tr>
<td>We need after-care services</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Quality of care is better in hospital</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Rural areas need CBS</td>
<td>2 (0.5%)</td>
</tr>
<tr>
<td>Hospital is central</td>
<td>2 (0.5%)</td>
</tr>
<tr>
<td>CBS are over-used</td>
<td>2 (0.5%)</td>
</tr>
<tr>
<td>Other reason</td>
<td>17 (4%)</td>
</tr>
</tbody>
</table>

### Table 7.16  Reasons Given for Choosing Curing Illness or Educating the Public about Health Risks

<table>
<thead>
<tr>
<th>Reasons given</th>
<th>No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>You have to cure / treat sick people</td>
<td>110 (28%)</td>
</tr>
<tr>
<td>Both are important</td>
<td>102 (26%)</td>
</tr>
<tr>
<td>Prevention is better than cure</td>
<td>96 (24%)</td>
</tr>
<tr>
<td>If educate people, may avoid illness</td>
<td>58 (15%)</td>
</tr>
<tr>
<td>You can only do so much with education</td>
<td>49 (12%)</td>
</tr>
<tr>
<td>Educate young people</td>
<td>17 (4%)</td>
</tr>
<tr>
<td>We have enough education now</td>
<td>6 (2%)</td>
</tr>
<tr>
<td>Need to fund research so can cure</td>
<td>4 (1%)</td>
</tr>
<tr>
<td>People need education</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Other reason</td>
<td>9 (2%)</td>
</tr>
</tbody>
</table>
Table 7.17  Reasons Given for Choosing Cancer Research or Intensive Care Units for People over 80

<table>
<thead>
<tr>
<th>Reasons given</th>
<th>No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer affects everyone</td>
<td>159 (40%)</td>
</tr>
<tr>
<td>Over 80’s have had a good innings</td>
<td>94 (24%)</td>
</tr>
<tr>
<td>Cancer claims too many lives</td>
<td>69 (17%)</td>
</tr>
<tr>
<td>Both are important</td>
<td>68 (17%)</td>
</tr>
<tr>
<td>Previous / personal experience</td>
<td>48 (12%)</td>
</tr>
<tr>
<td>Cancer research needs money</td>
<td>23 (6%)</td>
</tr>
<tr>
<td>Over 80’s entitled to good quality of life</td>
<td>13 (3%)</td>
</tr>
<tr>
<td>Important to find a cure for cancer</td>
<td>7 (2%)</td>
</tr>
<tr>
<td>Can’t refuse to treat over 80’s</td>
<td>6 (2%)</td>
</tr>
<tr>
<td>Intensive care is more urgent need</td>
<td>5 (1%)</td>
</tr>
<tr>
<td>Cancer affects children</td>
<td>5 (1%)</td>
</tr>
<tr>
<td>Already lots of cancer research</td>
<td>4 (1%)</td>
</tr>
<tr>
<td>Long term view</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Important to look after elderly</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Personal reasons</td>
<td>2 (.5%)</td>
</tr>
<tr>
<td>Other reason</td>
<td>12 (3%)</td>
</tr>
</tbody>
</table>

hospital system over CBS. While there was some support for CBS from health prevention and education perspectives, this was very much a minority view. There was an awareness of the value of health education in some of the comments in Table 7.16 but the emphasis on acute care remained the most prevalent comment.

In Table 7.17, both cancer research and care of persons aged over 80 years in intensive care units were seen to be important by 68 participants. However, the majority of comments placed a priority on cancer research with many participants not inclined to provide intensive care to elderly people.

The difficulty in choosing between one individual and another was evident in Table
7.18 with 128 participants unable to make a decision. There were a number of participants who rationalised their decision in favour of the mother with relatively few advocating for the child.

Table 7.18 Reasons Given for Saving a Premature Baby or a Mother

<table>
<thead>
<tr>
<th>Reasons given</th>
<th>No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can't choose between people</td>
<td>128 (32%)</td>
</tr>
<tr>
<td>Mother may have other children to care for</td>
<td>105 (26%)</td>
</tr>
<tr>
<td>Mother could have other children later</td>
<td>55 (14%)</td>
</tr>
<tr>
<td>Mother is established member of family/ community</td>
<td>43 (11%)</td>
</tr>
<tr>
<td>Premature baby may have long term health problems</td>
<td>42 (11%)</td>
</tr>
<tr>
<td>Baby has its whole life ahead of it</td>
<td>29 (7%)</td>
</tr>
<tr>
<td>Baby without mother is disadvantaged</td>
<td>12 (3%)</td>
</tr>
<tr>
<td>Depends on the situation</td>
<td>4 (1%)</td>
</tr>
<tr>
<td>Husband would want to save the mother</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Have been through this experience</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Religious reasons</td>
<td>2 (.5%)</td>
</tr>
<tr>
<td>Natural selection</td>
<td>2 (.5%)</td>
</tr>
<tr>
<td>Personal reasons</td>
<td>2 (.5%)</td>
</tr>
<tr>
<td>Other reason</td>
<td>4 (1%)</td>
</tr>
</tbody>
</table>

7.3.3.7 Underlying philosophical approaches

Participants were read out four things and asked “Thinking about the public health care system as a whole, which one of these things do you think is the most important?” These four options are given in Table 7.19 (next page), and represent four philosophical approaches: egalitarian; communitarian; utilitarian; and libertarian.

Comparisons.

There were no differences between the groups in the proportion of participants selecting “Being equally available to all” as the most important approach for the public health care system.
Table 7.19  Four Philosophical Approaches to the Public Health Care System

<table>
<thead>
<tr>
<th>Most important approach</th>
<th>No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being equally available to all (egalitarian)</td>
<td>291 (73%)</td>
</tr>
<tr>
<td>Providing the services which the community has decided it wants (communitarian)</td>
<td>49 (12%)</td>
</tr>
<tr>
<td>Helping the most people (utilitarian)</td>
<td>40 (10%)</td>
</tr>
<tr>
<td>Providing services according to one’s ability to pay (libertarian)</td>
<td>14 (4%)</td>
</tr>
<tr>
<td>Can’t say</td>
<td>6 (1%)</td>
</tr>
</tbody>
</table>

7.3.3.8 Emerging trends

The overwhelming view of participants was for an egalitarian approach to health care.

7.3.4 Decision making

7.3.4.1 Principles underlying health care decisions

Participants were presented with a series of options that were designed to elicit the principles underlying health care decisions. A sentence explained a particular situation and participants were asked to choose one of two options. Responses are presented in Table 7.20 (next page).

Comparisons.

There was only one significant difference between groups in responding to these four items. Older participants were less likely than younger participants to choose the statement that “Premature babies should be given intensive care regardless of their chances of survival”.

7.3.4.2 Emerging trends

These questions attempt to test whether participants are able to move from the abstract view of the health system as presented in Table 7.19, to the more specific
Table 7.20  Principles Underlying Health Care Decisions

<table>
<thead>
<tr>
<th>Alternatives presented</th>
<th>No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some people's behaviour contributes to their illness, for example people who smoke or drink excessively. Do you think that these people should:</td>
<td></td>
</tr>
<tr>
<td>Be treated the same as other people in the health system OR</td>
<td>301 (75%)</td>
</tr>
<tr>
<td>Have to wait longer for treatment?</td>
<td>73 (18%)</td>
</tr>
<tr>
<td>Can't say</td>
<td>26 (7%)</td>
</tr>
<tr>
<td>Dealing with a situation where there is something that cannot be available to everyone, for example an organ transplant where there is only one organ, do you think:</td>
<td></td>
</tr>
<tr>
<td>Everyone should be treated equally regardless of their age OR</td>
<td>177 (44%)</td>
</tr>
<tr>
<td>A young person should take priority over an older person?</td>
<td>173 (43%)</td>
</tr>
<tr>
<td>Can't say</td>
<td>50 (13%)</td>
</tr>
<tr>
<td>When deciding which services to put money into, the most money should be put into:</td>
<td></td>
</tr>
<tr>
<td>Services which help the sickest people OR</td>
<td>123 (31%)</td>
</tr>
<tr>
<td>Services which help the most people</td>
<td>235 (59%)</td>
</tr>
<tr>
<td>Can't say</td>
<td>42 (10%)</td>
</tr>
<tr>
<td>Premature babies should be given intensive care:</td>
<td></td>
</tr>
<tr>
<td>Regardless of their chances of survival OR</td>
<td>298 (75%)</td>
</tr>
<tr>
<td>Only when they have a very good chance of surviving</td>
<td>77 (19%)</td>
</tr>
<tr>
<td>Can't say</td>
<td>25 (6%)</td>
</tr>
</tbody>
</table>
situations presented in Table 7.20. The first question allowed participants to discriminate against people who had contributed to their illness. The majority response favoured the proposition that no discrimination should occur and this is consistent with the egalitarian view.

The second situation allowed for selection for organ transplantation on the basis of age. The responses indicated a more discriminating approach with the views equally divided between those who maintained the strictly egalitarian view and those who would favour the young person taking precedence.

When faced with a situation where a choice could be made between putting money into treating the sickest people or into services that helped the most people, the majority of participants favoured a more utilitarian approach. This response implies that the greater good can prevail over the idea of providing everything for everyone. It is consistent with the data presented in Tables 7.7, 7.12 and 7.17 about cancer research being preferred ahead of elderly patients in intensive care units.

Care of premature babies was strongly supported by the majority of participants regardless of their chance of survival. This could be seen to be contradictory to the previous point but reflects the difficulty in making decisions in this very sensitive area. It could be interpreted to mean that participants were able to see a longer-term benefit if the baby survived. Such a benefit would not be realised if an elderly person survived intensive care.

7.3.4.3 Who should make health care decisions?
Participants were asked if they agreed or disagreed with each statement relating to who should make the decisions about the health system. “Strongly Agree” was scored as 5, “Strongly Disagree” as 1. Responses are presented in Table 7.21.
Comparisons

There were several differences between groups in relation to these items. Men and older participants obtained a higher mean score than women or younger participants respectively for the item “If members of the community are involved in making decisions, only well educated, articulate people should represent the community”. Older participants obtained a lower mean score than younger participants for the item on a group of people contributing to decision making, indicating less agreement with this statement. Older participants obtained a higher mean, and upper SES participants a lower mean score for the statement that “Medical professionals should make all the decisions about the public health care system”. Participants from the upper SES suburbs obtained a lower mean score than participants from the lower SES suburbs for the statement “Politicians and administrators should make all the decisions about the health care system”.

7.3.4.4 Emerging trends

The data show very strong support for community surveys with 93% of participants agreeing with them. Developing groups to contribute to the decision making processes about major issues was also well supported by 77% of participants.

The responses do not support any particularly nominated group being favoured in the decision making process such as health consumers or well educated and articulate people. Medical professionals and particularly politicians and administrators received little support for making all the decisions about the health system.

The conclusion from this set of data is that community participation is viewed very positively but those involved should be representative of the community and not seen to have any special interest or bias.
<table>
<thead>
<tr>
<th>Statement</th>
<th>Mean</th>
<th>SD</th>
<th>Strongly Agree No. (%)</th>
<th>Agree No. (%)</th>
<th>Neither Ag / Dis No. (%)</th>
<th>Disagree No. (%)</th>
<th>Strongly Disagree No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surveys of the public's opinions like this one should be used in planning health services.</td>
<td>4.18</td>
<td>.70</td>
<td>119 (30%)</td>
<td>250 (63%)</td>
<td>14 (3%)</td>
<td>16 (4%)</td>
<td>1 (0%)</td>
</tr>
<tr>
<td>Some countries have a group of people from the community who contribute to making decisions about major issues facing the public health care system. Do you agree that that is a good idea?</td>
<td>3.78</td>
<td>.94</td>
<td>71 (18%)</td>
<td>237 (59%)</td>
<td>33 (8%)</td>
<td>52 (13%)</td>
<td>7 (2%)</td>
</tr>
<tr>
<td>If members of the community are involved in making decisions, only people who use the public health care system should represent the community.</td>
<td>2.62</td>
<td>1.08</td>
<td>17 (4%)</td>
<td>102 (26%)</td>
<td>26 (6%)</td>
<td>221 (55%)</td>
<td>34 (9%)</td>
</tr>
<tr>
<td>If members of the community are involved in making decisions, only well educated, articulate people should represent the community.</td>
<td>2.47</td>
<td>1.12</td>
<td>19 (5%)</td>
<td>84 (21%)</td>
<td>22 (5%)</td>
<td>214 (54%)</td>
<td>61 (15%)</td>
</tr>
<tr>
<td>Medical professionals should make all the decisions about the health care system.</td>
<td>2.42</td>
<td>1.16</td>
<td>22 (5%)</td>
<td>78 (19%)</td>
<td>19 (5%)</td>
<td>207 (52%)</td>
<td>74 (19%)</td>
</tr>
<tr>
<td>Politicians and administrators should make all the decisions about the health care system.</td>
<td>1.59</td>
<td>.70</td>
<td>2 (1%)</td>
<td>10 (2%)</td>
<td>7 (2%)</td>
<td>182 (45%)</td>
<td>199 (50%)</td>
</tr>
</tbody>
</table>
7.3.5 Health characteristics of participants

The responses of participants when asked how they would rate their health in general are presented in Table 7.22.

Table 7.22  Self-Rating of Health

<table>
<thead>
<tr>
<th>Rating</th>
<th>No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very poor</td>
<td>6 (2%)</td>
</tr>
<tr>
<td>Poor</td>
<td>22 (5%)</td>
</tr>
<tr>
<td>Good</td>
<td>145 (36%)</td>
</tr>
<tr>
<td>Very good</td>
<td>155 (39%)</td>
</tr>
<tr>
<td>Excellent</td>
<td>71 (18%)</td>
</tr>
<tr>
<td>No answer</td>
<td>1 (0%)</td>
</tr>
</tbody>
</table>

When asked if they have any longstanding illness or infirmity, 154 (38%) replied that they did, and 246 (62%) that they did not.

Almost all participants ($n = 365$, 91%) reported that they had consulted a general practitioner (GP) in the last 12 months. Of these 365 participants, 44 (12%) had consulted a GP more than 12 times, 52 (14%) 7 to 12 times, 139 (38%) 3 to 6 times, 76 (21%) twice, and 54 (15%) had consulted a GP once in the last 12 months.

All participants were asked if their GP bulk bills to which 248 (62%) replied yes, 131 (33%) no, and 21 (5%) could not say.

Just over one quarter ($n = 109$, 27%) reported that they do smoke cigarettes, 290 (73%) reported that they did not, and one participant did not answer this question. Less than half of participants have private health insurance ($n = 189$, 47%), 210 (53%) reported that they did not have private health insurance, and one participant did not answer this question.
7.4 Summary

This survey is a serious attempt at understanding community views on a range of matters about the public health care system in Geelong. The data show a rich variety of views exist with many common threads able to be identified. These will be explored in a great deal more detail in Chapter 8 when the reflections from both pieces of this two part research study are considered. However, there are some general comments about the limitations of the data that should be made at this point.

Many of the questions asked in the telephone interviews related to issues about which there has been little public debate or information readily available. Participants are therefore unlikely to have thought about these issues before the interview. The responses given may be unconsidered and perhaps unreliable. One of the disadvantages of this type of survey methodology is that it does not allow time for participants to reflect on the issues raised. The interviewers reported that participants found a number of questions difficult to answer. If the community is to be involved in making decisions about priorities in health care, there is a need for public education about the major issues facing the public health care system.

The response rate was quite low, and indicates that some caution should be used in generalising from these results. The interviewers reported that many people refused the interview because of its length (20 minutes). They also found young men a very difficult group to recruit, suggesting that the young men interviewed are not representative of young men in general in the Geelong area. Notwithstanding, the sample of 400 does have sufficient statistical reliability to encourage further debate and to enable some conclusions to be reached. More of that in Chapter 8.
Chapter 8
Summary and Conclusions

8.1 Introduction
This thesis set out to answer four research questions. These were to:

1) Identify the priorities and expectations that the Geelong community has of its public health care system.

2) Determine if there is a common view on the attributes of a just health system.

3) Consider a method of utilising the data in the determination of health care priority setting in Barwon Health.

4) Determine a model of community participation that enables ongoing input into the decision making processes of Barwon Health.

This concluding chapter summarises the findings of the research in a form consistent with these questions. The chapter examines each research question by synthesising the data, both qualitative and quantitative, and identifies a number of findings that emerge. Finally, a set of proposals to address these findings is offered.

8.2 Identification of the Priorities and Expectations that the Geelong Community has of its Public Health Care System
The Geelong community highly values the services provided from its public health care system. It considered the services of Grace McKellar Centre, The Geelong Hospital and community based services to be better than average and overall, about 20% better than the Victorian public health care system (Table 7.10). This is consistent with survey questionnaires that have been undertaken on patients from The Geelong Hospital (DataTab, 2000; TQA Research, 1997). On two separate occasions, these independent surveys have assessed patient satisfaction at The Geelong Hospital to be at levels that exceed any other health service in Victoria.
8.2.1 Priorities

When participants were asked the open questions about what services were most important for the public health care system to provide and where more money should be spent, the most frequently mentioned responses were:

- hospitals or more hospital beds;
- emergency services;
- aged care;
- more doctors or more staff; and
- shorter waiting times. (Table 7.3)

When asked to rank the importance of services, the participants responded in an order that was broadly consistent with a survey conducted in the United Kingdom by Ann Bowling (1996). In Bowling’s survey, a slightly different question was asked and the top ranking was given to treatment to children with life threatening illnesses. Emergency services was not offered as an option by Bowling but interestingly, the two choices may be interchangeable with the Bowling option being a possible sub-set of emergency care. The Geelong survey compares with the findings of Bowling as shown in Table 8.1.

<table>
<thead>
<tr>
<th>Geelong Survey</th>
<th>United Kingdom Survey (Bowling, 1996)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Emergency services</td>
<td>1. Treatments for children</td>
</tr>
<tr>
<td>2. Special care and pain relief for the dying</td>
<td>2. Special care and pain relief for the dying</td>
</tr>
<tr>
<td>3. Preventive screening and immunisation</td>
<td>3. Preventive screening and immunisation</td>
</tr>
<tr>
<td>4. Aged care services</td>
<td>4. Surgery that assists in everyday tasks</td>
</tr>
<tr>
<td>5. Services for people with mental illness</td>
<td>5. District nursing and community services/ care at home</td>
</tr>
</tbody>
</table>

In the Bowling (1996) survey, aged care services were not offered as an option and services for people with mental illness ranked in sixth position. In the Geelong survey,
surgery such as hip replacements ranked sixth and district nursing was not offered as an option. The similarities in the data are quite striking and confirm that priorities are not necessarily unique to local communities.

When asked to choose if it was more important to fund hospitals or community based services, hospitals were selected by 60% of participants (Table 7.7). This emphasis on hospitals and doctors in participants' responses suggests that the community focuses on illness and its treatment rather than on preventive health when thinking of the public health care system.

Other questions designed to elicit priorities continued the theme of acute care receiving preference. Nursing was viewed as a high priority with 90% of participants agreeing that additional funds should go to employing additional nurses (Table 7.5). In a seemingly contradictory view, health education in schools was also strongly supported with 80% of participants favouring an increase in funding.

When participants were asked to identify sources of funding there was a strong emphasis on increasing taxation revenue from a range of areas. This finding suggests that the community may be prepared to pay more in taxation if there are real improvements in the provision of public health care services.

In more specific questions about priorities (Table 7.7), participants considered that it was preferable to fund cancer research than to care for people over 80 years in intensive care units. When asked to consider spending limited funds to save either a mother or her baby, 50% of participants chose to save the mother but 41% were unable to make a choice.

Bowling's (1996) study showed that 42% of her sample supported discrimination against people who had contributed to their illness. The Geelong participants were not as strong on that point with only 18% suggesting these people should wait longer for treatment (Table 7.20). Participants were also unable to discriminate in favour of a younger person when faced with a choice between an older and younger person for organ transplantation (Table 7.20).
However, 75% of participants believed that premature babies should be given intensive care regardless of their chances of survival (Table 7.20). This indicates that the community is prepared to discriminate on the basis of age given the reluctance to support persons aged over 80 years receiving intensive care.

Priorities may be influenced by personal experience and media coverage. In a city like Geelong, which has its own daily newspaper, the public health system is a good source of news, both good and bad. When issues are raised in the large Melbourne daily media, The Geelong Advertiser will usually want to place its own local flavour to the issue.¹ This frequently results in media attention that is then published to the community. It would not be surprising that this would influence the community’s view.

Overall, the data show a strong awareness of the needs of the acute and aged care sectors with little recognition of those services provided in a non-institutional setting. When asked where money should be spent, preferences were generally towards the same acute and aged care sectors. The one exception was a modest increase in interest towards putting money into research although this area was not identified more generally as of much importance.

The community survey results summarised above were broadly consistent with the qualitative research undertaken. The focus groups valued the fact that a health service was available to the Geelong community and that it was available, accessible and free. Most focus groups acknowledged the quality of services delivered and the clinical excellence in medical and nursing staff. Services valued tended to be in three areas. The highest priority services were in the acute areas including emergency and critical care services. The next set considered the sub-acute areas of rehabilitation and after care. The final set covered the more community-based services.

Mental health services, illness prevention and research did not take prominence with many focus groups indicating a far greater awareness of the issues likely to confront participants personally. This conclusion highlights the difficulty that is faced by asking

¹ Personal observations of the author who was Chief Executive of Barwon Health 1998-2000.
individuals to consider issues where knowledge and understanding of the health system is limited.

The highest priority of the focus groups was around access to acute care, which is consistent with the issues raised in the community survey. However, it is interesting that there was no general view by the focus groups about specific services that should be given priority. Aged care was raised by a majority of groups but other services such as mental health, children and young people’s health were mentioned by only two groups. It may be that the community needs to be made aware of the issues and conflicting priorities that do exist and it cannot be assumed that, in the absence of such information, knowledge will abound. One issue that has received a great deal of coverage in the media is the ageing population. While this is a matter very relevant to all members of the community who have a relative, friend or are themselves confronting old age, the high media exposure may have influenced the thinking of the focus groups where it was accorded a high priority.

The focus groups were unable to reach agreement on all but the last of the forced choice scenarios. The difficulty that they experienced was anticipated but the comments did tease out some views that suggested that hard choices could be made if there was sufficient information given. The groups were able to reach a view on the question of the mother or the baby with the majority opting to support the mother. The real issue is how the groups would vote if they were not dealing with an issue in abstract but were considering an actual case that was well known to them personally or had received extensive media coverage.

8.2.2 Expectations
The main areas participants perceived as problems in the public health care system related to waiting and to funding or staff shortages (Tables 7.8 and 7.9). The open question about shortfalls in the public health care system elicited many responses related to the problem of waiting. Waiting for elective surgery was the most frequently given response, mentioned by just over a third of participants. Waiting to get into hospital, waiting in the emergency department, waiting for a specialist, and waiting for a general practitioner were each mentioned by 10% or more of participants. The only other shortfalls mentioned by 10% or more of participants were staff shortages, funding
shortages and beds closing. Having to wait too long for treatment was rated as a serious problem by 73% of participants, and staff being too busy by 72% of participants.

It can be deduced from these data that there is an explicit expectation that the Geelong community should not have to wait for access to the public health care system or wait to consult with medical professionals in the private sector.

This expectation confirms the view of Daniels stated in Chapter 2 for a “fair equality of opportunity” where health consumers should be entitled to a fair share of the normal opportunities present and barriers should be reduced to enable this to occur (Daniels, 1985 as cited in Beauchamp & Childress, 1994, p. 340). While this notion of justice and fairness is a common expectation, the way of achieving it varies from country to country. Both the United Kingdom and the United States of America (USA) would claim to have these objectives, but the universal access aspects of the British system can be contrasted to the more libertarian approach in the USA. Notwithstanding the American Medicare and Medicaid initiatives that aim to secure services for the elderly and the poor, there are large numbers of the population who cannot afford to access their health system. For that cohort of the population, the system would be reasonably perceived as neither just nor fair. This matter will be further discussed later in this chapter.

The focus groups identified waiting times, concerns about doctors and funding issues as the major shortfalls of the public health care system. Funding impacted on staffing levels and dental services. Funding of the health system is a recurring theme whenever and wherever issues about health systems are raised. If funding was not an issue then there would be less need to consider priority setting processes as everyone could receive all the services they thought were needed. The awareness of the focus groups about this issue is an indicator of the publicity that it attracts as many of the comments reflected the very real problems that funding pressures dictate.

Responses to the specific questions about interactions with health professionals suggested that participants were generally satisfied with how they were treated. Few participants raised concerns about the behaviour of health professionals. This finding is somewhat different to that of the focus groups in which many participants discussed
problems related to the behaviour and communication skills of doctors and specialists. The conclusion that can be drawn is that the Geelong community expects to be respected and listened to by their medical professionals. They also expect to be communicated with in a clear manner. The majority of the participants believed medical professionals acted in this way.

A series of questions enabled some conclusions to be reached about what participants expected from the public health care system (Table 7.14). Choices were made between the three variables of quality, timeliness and cost. The majority of participants placed quality ahead of timeliness and cost. A smaller majority placed timeliness ahead of cost. While the data show that there is some variation between the higher and lower SES in relation to the impact of cost, it can be concluded that the Geelong community expects to have access to high quality services in a timely way. For many people, the cost of that service is less relevant.

The majority of participants identified a range of Government revenue raising opportunities as the preferred source of funding that would enable appropriate access to a quality system (Table 7.6). Increasing taxation was the most popular choice. Revenue raising by Government may be perceived as a more palatable option to addressing the issue of scarcity as discussed in Chapter 3 but is likely to be a more short term option than one of an enduring nature that eliminates the problem. In reality, the problem as defined in Chapter 3 is such that an infinite demand makes some form of priority setting inevitable.

8.3 Determination of a Common View on the Attributes of a Just Health System

The questions that were asked of the focus groups and in the community survey aimed to determine if there was any particular form of distributive justice that was favoured by the general community.

The conclusion reached from reviewing the data from the focus groups was that there was a divergence of views but the common thread was that the groups supported an egalitarian approach that embraced the concept of community participation. An even
stronger direction of egalitarianism was evident in the community survey with 73% of participants favouring an egalitarian approach to health care (Table 7.19). Whereas in the focus groups there were three male groups that did not reach a consensus view about this matter, there were no significant differences across the stratified groups in the community survey.

While some participants were prepared to discriminate according to behaviour and age, there was an overwhelming commitment to maintaining an egalitarian approach. Participants generally accepted that there was an argument in support of discriminating in favour of the younger person compared to an older person but were reluctant to make a choice as they felt that they did not have a right to discriminate in this way. The egalitarian approach was also supported when lifestyle choices were postulated as a reason for discriminating against certain people. It was evident that there were challenges in drawing participants down from the general proposition to a more particular proposition. The theoretical willingness to discriminate for example against an elderly person may be agreed when considered impersonally but far more difficult to implement in practice.

Further confirmation of the community view in favour of an egalitarian approach is the data presented in Chapter 7 that shows three-quarters of participants indicated that people whose behaviour has contributed to their illness should be treated the same as other people in the health system (Table 7.20). However, there were two occasions when participants tended to give some priority to younger people over older people. When presented with a situation where there is something that cannot be available to everyone, such as an organ transplant where there is only one organ, 43% of participants indicated that a young person should take priority over an older person. Cancer treatment was chosen as being more important to spend more money on in preference to intensive care units for people over 80 by 72% of participants. One of the most frequently mentioned reasons (24%) for this choice was that people over 80 have had a good innings. The egalitarian view was again in evidence with 40% of participants giving the fact that cancer affects everyone as a reason for choosing cancer research (Table 7.17).
These views are consistent with Dicker, a general practitioner and Armstrong, a sociologist, (Dicker & Armstrong, 1995) who surveyed British patients about priority setting. Their results confirmed the notion of equity in priority setting but their data show a preparedness to discriminate in favour of the young and against the elderly.

In an Australian survey of health issues, Nord, Richardson, Street, Kuhse, and Singer (1995) tested whether health benefit maximisation took precedence over egalitarian objectives. In considering an economic argument in favour of the utilitarian approach, Nord’s study population found strongly in favour of egalitarian principles.

The strong push by participants for a health system that is equally available to all is consistent with the views of John Rawls (1973) reported in Chapter 2 and Daniels (1985 as cited in Beauchamp & Childress, 1994, p. 340) who has been already mentioned in this chapter. The notion of “fair equality of opportunity” would seem to be confirmed by the Geelong community. It is also an endorsement of one of the objectives of the Australian Medicare system reported in Chapter 1 which, among other things, aims “to give all Australians access to health care services with priority according to clinical need” (Health Insurance Commission, 2001).

In Chapter 2, the case for an egalitarian approach is argued and bears repeating in this final chapter because it identifies the non-discriminatory ideals of a just community. However, its application into the area of resource allocation is more problematic. The objective of seeking a fair opportunity to access health care implies an ability of the system to provide such a service and this will not always be possible. The issue of rationing becomes a feature of the system in such circumstances and this means that one area assumes a higher priority than others do. The egalitarian interpretation must take rationing into account and its integrity as a theory will be maintained only if all persons accessing the system are faced with the same range of alternatives. Rationing therefore needs to be effected in an egalitarian way so there is no discrimination within the area of service even though there may be discrimination between two competing services.

This distinction is important when considering the issue of providing cardiac surgery at The Geelong Hospital or expanding other services. The theory of egalitarianism can assist by considering the community’s ability to access a range of services and ensuring
that all persons have access to a decent minimum range of services. While cardiac surgical services would presumably be defined by the community as being part of that decent minimum range of services, the location of these services then becomes relevant. Access to Melbourne based services would be consistent with the type of access given to the rest of rural and regional Victoria for cardiac surgery and could be argued to be reasonable for the Geelong community. This solution would remain consistent with egalitarianism. The issue becomes one of defining the services required and ensuring all have a fair opportunity to access them. When considering the implications for the future, this is an important point to keep in mind.

8.4 Utilisation of the Data in Barwon Health’s Priority Setting

Data collected in this thesis provide a profile of the Geelong community, its priorities, expectations and values that has not previously been available. As such, it represents a rich source of information that can be used as the Board of Directors of Barwon Health sees fit. In many respects, the data set the themes for future interactions with the community and preferred methods for decision making that are commented upon later in this chapter. The data also need to be viewed keeping in mind the limitations of its sampling and methodology.

Many of the questions asked in the telephone interviews related to issues about which there had been little public debate or information readily available. Participants were unlikely to have thought about these issues before the interview. The responses given may therefore be unconsidered and perhaps unreliable. One of the disadvantages of this type of survey methodology is that it does not allow time for participants to reflect on the issues raised. The interviewers reported that participants found a number of questions difficult to answer. In particular the forced choice type questions reported on in Table 7.7 proved impossible to answer for up to 41% of the participants.

The response rate was quite low, and indicates that some caution should be used in generalising from these results. The interviewers reported that many people refused the interview because of its length (20 minutes). The interviewers also found young men a very difficult group to recruit, suggesting that the young men interviewed are not
representative of young men in general in the Geelong area and that for young men, health is not a priority issue.

Dolan, Cookson and Ferguson (1999) claim that the public’s views about setting priorities are “systematically different” when they have been given an opportunity to discuss the issues. They contend that when the public discuss matters at length, their views change. They admit that other studies that elicit people’s initial reactions generate similar results to those, such as focus groups, that elicit more considered reactions. The results of the Geelong telephone survey would seem to be reasonably consistent with the views of the Geelong focus groups. Indeed, there is a remarkable synergy between the results of both and the only major variations seem to be in the priorities given in the focus groups to improving communication with medical professionals and to improving dental services.

In summary, the data present a range of information that can be used to inform the planning processes of Barwon Health. An early community survey in the NHS exploring priority setting was seen to be a “stimulus for further discussion of these very complex issues” rather than “as a basis for health service planning” (Bowling, Jacobsen, & Southgate, 1993). While these data should be seen as the first step in understanding how the community thinks about its public health care system, there are some important messages that can be taken from the data.

Later in this chapter, implications of these findings for Barwon Health will be explored with a number of directions identified. Barwon Health’s Board of Directors may wish to pursue these if it is to continue its commitment to community participation in its decision making and priority setting processes.

8.5 Determining a Model of Community Participation

Chapter 4 detailed a range of opportunities for community participation in the health care setting. Traditional ways of involving the community in the governance arrangements in Victoria’s public health care system continue to this day with Boards of Directors appointed by the Government to oversee the organisation and management of, in some cases, extremely large corporations.
The community may not perceive board membership as being a relevant means of input as the backgrounds of the vast majority of Directors show a strong selection bias towards those with professional backgrounds. Indeed, until the State Government accepted the recommendations of the Ministerial Review of Health Care Networks in 2000, there was no requirement to appoint a Director who could give a consumer perspective (Duckett et al., 2000). The lack of consumer recognition in Board memberships was a theme in numerous submissions to this Review and the report noted the demand for “consumers’ needs and preferences to be properly considered in the decision making process of health care organisations.” The appointment of at least one person who was able to reflect the perspectives of users of health services was to ensure that the Board and Chief Executive did not “lose sight of the of the organisation’s core purpose and the interests of the people it exists to serve” (Duckett et al., 2000, p. 75).

While the implementation of this policy into Victoria’s public health services gives some recognition to the role of consumers, it does not address the broader range of community input that may benefit the decision making processes of these organisations. The model of community advisory committees outlined in Chapter 4 does provide a more systematic approach to community participation than has been previously available in Victoria. The community advisory committee initiative was a further recommendation from the Ministerial Review of Health Care Networks (Duckett et al., 2000) and requires models of community participation to be developed that enable the meaningful input of the community. The community advisory committee has a direct reporting relationship to the Board of Directors of the health service and amongst other things, should be involved in determining the strategic directions of the organisation in service development, monitoring the needs of health service users and their access to these services. A major function of the community advisory committee is to ensure and promote community participation across the health service.

The Victorian public health system is now engaged in implementing the community advisory committee model and the outcomes of this study assist in informing how the broader implementation challenges can be effected. To be effective, the community advisory committees will need to take a leadership role in establishing models of community input that will ensure a broad base of participation. While the committees will be diverse in membership, it is impossible to contemplate that they will be a truly
representative community body. In essence, community advisory committees will be an overarching committee that should stimulate and actively promote further models of community participation.

In fulfilling their charter, Victoria’s new community advisory committees of health services need to develop community participation models that are flexible and provide meaningful input to the decision making processes of the public health care system. It is timely at this point to restate some of the opportunities that may be useful in considering means of community input. These include:

- Surveys and opinion polls;
- Rapid appraisal;
- Public meetings;
- Focus groups;
- Standing panels;
- Citizens’ juries;
- Deliberative polls; and
- Future search conferences.

When participants in this study were asked questions about who should make decisions about the public health care system, there was considerable support for members of the public being involved. Almost all participants agreed that a survey of the public’s opinions, like the one they were involved in, should be used in planning health services. There was very little support for politicians and administrators making all the decisions about the health system and only limited agreement with the statement that medical professionals should make all the decisions about the health care system (Table 7.21).

In considering the support of this sample for public involvement in making decisions about the public health care system, it should be noted that only 30% of those contacted were willing to be interviewed. It is possible that the sample was biased in favour of those who do support community participation, as indicated by their willingness to be interviewed for this study. Similar comments could be made about focus group participation.
The principle and techniques for community participation are well supported by Governments,\textsuperscript{2} communities (e.g. Bowling, 1996) and researchers (Billings & Cowley, 1995). Data from the focus groups and the community survey suggest that there is strong support for community surveys and focus groups as a means of community participation. Focus group participants also expressed support for the concept of citizen's juries.

Jordan, Dowswell, Harrison, Lilford, and Mort (1998) cast doubt on the validity of one off consultation exercises and suggest that proper structures and mechanisms for sustained, meaningful communication and action are needed. While the first proposition is arguable, the idea that enduring mechanisms need to be in place would seem to be appropriate. The results of this study tend to support the one off community survey as being a useful snapshot of community views at a particular point in time. Participants in the survey have suggested other means of input as also being useful but that does not necessarily underplay the community survey.

There are frequently people in the community who purport to represent the views of the community but do so with little attention given as to how they are able to represent a community view. The importance of this study in its approach to community participation is that it has at least gained a community perspective through a rigorous process of objective measurement and analysis. In so far as the sample is representative of the broader community, the conclusions can fairly represent that community. Properly conducted community polling is considered to be a legitimate means of determining a community view.

The implications of community participation on the broader health care environment will be further discussed later in this chapter.

8.6 Implications for Barwon Health

The usefulness of this type of research is in its ability to be translated into practical actions that can improve the way that health services are conducted. One of the reasons that Barwon Health supported the study being undertaken was the recognition that the

\textsuperscript{2} Notably in Sweden, United Kingdom and Victoria, Australia
level of financial resources available to meet health needs was simply insufficient to meet the demands of the community. Shortfalls were reflected in extensive waiting times for elective surgery and increasingly longer waits for emergency care. Competing priorities were also prevalent and the difficulties in some services in keeping up with demand were providing internal tensions within the organisation. Increasing emphasis on tertiary services, such as cardiac surgery, was perceived to be to the detriment of other services that remained in strong demand but had diminished capacity to treat, such as orthopaedic surgery.

A further driver for the study was the frustration being experienced by senior clinicians who were being subject to significant pressures from their colleagues, patients, families and carers. They were seeking unrealistic levels of care when the outcomes were known to be, at best, poor or more inevitably, fatal. These clinicians were seeking guidance about what community standards were in relation to these matters. They wanted to be able to say to those making demands upon them that it was the community’s expectation that there is a time when “enough is enough” and that death is not the worst option in certain circumstances.

As a consequence of the findings of this study, a number of points can be made that may be of assistance to Barwon Health. These are presented as responses to a series of questions under the following headings:

- How can the findings on priorities and expectations be used?
- What does this mean for the allocation of resources?
- What are the preferred models for community participation?
- How does this process assist clinicians?

8.6.1 How can the findings on priorities and expectations be used?

One way of using the findings at a strategic level is to inform the Board of Directors about community priorities and expectations. The findings of the study provide an important contextual framework to the strategic planning processes in which the organisation is involved and presents very clearly where the community views the emphasis is needed.
Clearly, the issue of access to services for emergency and elective care is an absolute priority and waiting times at numerous levels in the system are a major issue to be overcome. This orientation to acute services is not surprising. The extensive recognition given by the media to these types of problems in the public health care system ensures a higher degree of knowledge than in other areas of the system. For many people, hospital services are their major source of interaction with public health care and knowledge based on personal experience is far more likely.

The Victorian Government also has the same priorities in this regard. At a recent address, the State Minister for Health, Hon John Thwaites named the Government’s key areas as:

- Reducing the incidence of ambulances by-passing hospitals because of emergency demand pressures;
- Improving elective operating waiting times;
- Reducing aggregate waiting lists; and
- Meeting financial budgets.\(^3\)

As stated earlier in this chapter, expectations of the public health care system are for timely access to services but this should not be at the expense of quality. While cost is a lesser issue for some, the opportunity for increasing charges from an individual health service is not an option currently available under the Government’s funding rules. This is a matter for further consideration under the broader system wide implications to be discussed later.

The agenda for the Boards of Directors of public health services is to address the priorities of the State Government in a proactive way to ensure the satisfaction of both consumers and the Government. However, the study has also identified priorities in other areas that also require a sharp focus. Caring for the dying, preventive screening and immunisation, aged care services and services for people with mental illness all rank highly in the minds of the community surveyed.

\(^3\) In a private meeting with the Author and others on 7 March 2001.
The development of a strategic approach to these areas is indicated from this study. This may be as part of the formal strategic planning process or through a particular focus in the budget allocation process undertaken annually within the organisation.

8.6.2 What does this mean for the allocation of resources?

Resource allocation in public health services is largely based about programs of care with the major areas being in acute care, aged care, mental health and community based services. The opportunity to transfer resources between these "silos" of funding is restricted by Commonwealth and State Governments but there are discretionary areas within each program of care. The budget allocation process is somewhat restricted as a consequence but the discretionary areas do permit some internal priority setting.

Given the discussion in the previous section, a process of allocating resources within the acute program towards those areas of higher community priority would seem to be indicated. A large range of services is provided to the community by organisations like Barwon Health. Some of these services are duplicated by other health service providers or are unable to be delivered in a cost effective way. All are capable of being rigorously reviewed and processes should be put into place to allow this to occur.

The discussion in Chapter 2 about the ethical framework for making decisions of this nature is relevant here. An egalitarian approach would ensure equal opportunity to access a decent minimum range of services. This does not mean that all services must necessarily be provided by the one organisation, in this case, by Barwon Health. It is therefore consistent with an egalitarian theory for services to be restricted at one location so long as alternative services are available and accessible elsewhere in the public health care system.

In reviewing those services that are highly expensive and that are available elsewhere, the discussion about cardiac services in Geelong is worthy of review. This service has a very short waiting list and there is some capacity within other Melbourne cardiac services to carry the workload of Barwon Health. Freeing up that resource would enable an aggressive approach to meeting other areas of high priority and satisfying both community and Government objectives. The implications of such a decision on Barwon Health may make it not worth taking this course of action as a campaign to
retain the service locally would most assuredly be undertaken. In such an event, the 
realpolitik of the situation may prevail. However, it is exactly this type of choice that 
this study is inviting and in a climate of scarcity, difficult issues are raised and 
courageous organisations will address them.

Ceasing a service is of course only one option that could be pursued and is possibly the 
most provocative but it is useful to demonstrate the point that there are no easy 
decisions in resource allocation. There are other areas within the community based 
services that could usefully be reviewed to assist in addressing the nominated priorities 
in the special care for the dying and preventive screening and immunisation. These 
areas are not the sole responsibility of Barwon Health with other key players being the 
Commonwealth, State and Local Governments. It is likely that a joint approach to the 
issue with other health care providers and key stakeholders in the region will be 
necessary if there is to be any change to the allocation of resources.

8.6.3 What are the preferred models for community participation?
As previously discussed, the preferred model of community participation in the State of 
Victoria is to establish a community advisory committee at each Metropolitan Health 
Service. This has not been mandated for regional and rural health services of which 
Barwon Health is one, but the size and complexity of Barwon Health suggest that it is 
appropriate to follow this direction. As discussed in Chapter 5, Barwon Health is 
advantaged in developing models of community involvement because of its location and 
the close affinity that the Geelong community has with its health facilities.

The study clearly identifies the willingness of the community to be consulted on matters 
relating to the development of public health care services. The findings of this study 
demonstrated the useful role community surveys and focus groups can play. The 
participants in the focus groups also had some priority to citizens’ juries as a means of 
community participation. The implication for Barwon Health is that there is now an 
expectation, at least in part of the community, for an ongoing dialogue about the 
planning of health services. The most opportune technique to engage the community is 
to adopt the model of community advisory committees that is being implemented in 
Melbourne.
The community advisory committee model is only one means of input and there is a need to develop complementary mechanisms to ensure the widest possible input on key issues. The community advisory committee should be established with agreed terms of reference and specific objectives that are agreed between it and the Barwon Health Board of Directors. As with its Melbourne counterparts, Barwon Health should report to the Minister for Health and the community annually on the activities of its community advisory committee and how it has responded to the recommendations and advice given.

The importance of the community advisory committee is that it provides a conduit for advice from a range of community sources. For this reason, the community advisory committee should be encouraged to establish linkages with other key groups within the community who would have a special interest in the matters of Barwon Health. These may be consumer groups, other providers, or simply community groups that exist for totally different purposes such as elderly citizens groups.

The Barwon Health Board of Directors may wish to seek advice on a specific matter and refer this request to the community advisory committee. In turn, the community advisory committee could then establish a process to elicit a broad range of responses from which to provide an informed view back to the Board. Techniques that could be considered are those already mentioned in this chapter and in Chapter 4 but those that seem to be most popular by the participants in this study are focus groups and community surveys.

As with all new initiatives, there will be costs associated with the establishment of models of community participation. This may require some financial support but this will be negligible in the context of the benefits being returned. There will also be challenges to the traditional power bases within the organisation when the community is consulted on matters that may have been the province of particular professional groups.

8.6.4 How does this process assist clinicians?
In Chapter 5, discussion centred on the difficulties and frustration experienced by the Director of Intensive Care in his attempts to rationally use the resources available to him. When declaring his position to the patient’s family he was labelled as “heartless
and uncaring”. This study provides a rich source of data that clinicians like the Director of Intensive Care may find useful.

The responses to the questions that required a choice in both the focus groups and the community survey disclose a willingness on behalf of some of the community to make the hard choices that are necessary in an environment of scarce resources (refer Tables 7.7 and 7.15-7.18 in Chapter 7). While many participants considered they were unable to make a decision and were unwilling to “play God”, there was a recognition that choices needed to be made. There was also recognition that making decisions in an abstract way may result in a different position to when there is a more personal involvement.

Table 7.12 in Chapter 7 discloses some very useful data for clinicians. These data show that 93% of participants considered it important for patients to have a say in decisions about their medical treatment. When asked whether quality of life should be considered in deciding whether to use lifesaving treatment or technology, 85% said that it should be considered. Opinion was more divided about whether to continue active treatment when there was likely to be little hope of success. The view of 87% of participants was that society needed to be more accepting of death.

This latter point is one worth pausing upon because it is a finding that challenges the thinking of all members of a community. Ways of educating the society about the inevitability of death would not seem to be as difficult as developing a view as to how the health system should deal with patients and their families, carers and friends when death is imminent. This study finds that opinion is divided on the question of continuing care when the prognosis is extremely poor with 46% of participants agreeing that active care should proceed (Table 7.12). There would seem to be a need for further work to be undertaken to better understand the somewhat contradictory findings that, on the one hand, death needs to be accepted but on the other hand, active care should continue to be provided despite the inevitable outcome of death.

These data identify some important signals for clinicians. They indicate that there is a preparedness by the community to consider the implications of active treatment and the
use of sophisticated technologies for people with a poor prognosis. The preference to invest in cancer research ahead of intensive care for patients over 80 years of age (Table 7.7) is a further indication that the community does not categorically support the proposition that everything that can be done, should be done.

At an operational level, the values and attitudes that have been identified can assist in developing internal systems that promote discussion and debate, not only among health professionals, but also with their patients, families and carers. The dilemmas faced by clinicians are typically complex. The example presented in Chapter 5 about the Director of Intensive Care who was criticised by a patient’s family for suggesting that active care of the patient should cease, is not an isolated event. Clinicians would be supported by organisations formalising their policies on these matters. The data received from this study can assist in this process.

Policies that promote and facilitate discussion need to be developed in the context that most focus groups in this study had difficulty reaching a consensus on some of the questions. Many participants in the community survey also responded with “can’t say” when challenged with having to make choices. This reinforces the difficult situation faced by clinicians, a difficulty rarely acknowledged by the community. Greater discussion about these issues will not only assist in the community becoming more aware of the choices that have to be made, it will also enable a better appreciation of the challenges that confront clinicians and administrators on a regular basis.

Clinicians interface with patients and their family, carers and friends at an extremely stressful time. The ability of clinicians to deal with these circumstances is a reflection of their own background, personality, training and personal characteristics. Their ability to cope is also linked to the repetitive nature of some of these situations and ultimately they can be worn down by the resultant stress. Systems of support need to be developed to assist clinicians at these times so they do not feel isolated or alone in having to deal with these difficult questions. This study provides some perspective for these clinicians.
8.7 Implications for Public Health Care

This chapter has already explored the implications of this study for Barwon Health and many of the comments contained in that analysis could reasonably be translated to the broader domain of public health care. There are several specific areas that require further exploration to complete this study. These will be presented under the following headings:

- Implications for Government policy;
- Implications for resource allocation; and
- Implications for the community.

8.7.1 Implications for Government policy

There have been several references in this thesis to the work of David Hunter (1997) and his assessment of the way Governments deal with the issue of rationing in health care is to “muddle through elegantly” and rely upon the “realpolitik” of decision making. The experience in Australia endorses this assertion. The thought of rationing in any explicit way seems to be anathema to politicians of any persuasion and this has been evident through the development of this study.

The need for the State Government to be involved in the planning of health services seems so obvious that it ought not to be mentioned. In Victoria, the State Government is developing its health planning focus but, other than the initiatives it outlined in the 1999 election, there has been limited public documentation on how health services are to develop in this State. This paucity of planning direction is not a new phenomenon. The Ministerial Review of Health Care Networks identified the need for a more systematic approach to planning health services and recommended the creation of a Health Services Planning Council (Duckett et al., 2000). This recommendation came on the back of a similar recommendation from a panel set up by the previous State Government, the Metropolitan Hospitals Planning Board, that a Planning Authority be established (Metropolitan Hospitals Planning Board, 1995). The recommendations of these successive, independent reviews were not accepted by the Government to whom they reported, despite almost unanimous support for their other recommendations. While the rationale for rejecting the recommendations is not clear, it could be speculated that the desire was to retain the power as close to the Minister and his
Department as possible and eliminate any conflict with a potentially independent planning body. *Realpolitik* would tend to support such speculation.

An implication of this study is that, in the absence of a service planning framework, priority setting will be forced upon individual organisations that are struggling to balance the competing demands of their communities and the Government. If the experience of Barwon Health can be taken as an example, faced with a resourcing dilemma, one option is to reduce its cardiac surgery and to allocate these resources into the areas of greater demand that include general surgery, orthopaedic surgery, cancer services and renal medicine. This re-allocation maintains Barwon Health’s commitment and that of the community, to an egalitarian approach but also recognises the long waiting lists and pressures in these other areas where Government has a priority to impact. While access to cardiac surgery would still be available in Melbourne, the *realpolitik* may be that the service must continue in Geelong.

If the State Government is serious about avoiding the repercussions of individual organisations allocating their own priorities, albeit after consultation with its community, then it must develop a planning framework in which sensible decisions can be made. The environment is ripe for this to occur, particularly in Melbourne where twelve new Metropolitan Health Services have been established with new Boards and new Chief Executives. All of the services are required to develop strategic plans during 2001 and these need to be consistent with the planning framework of Government. The input of a range of community representatives is foreshadowed in the development of these plans and is mandated for the community advisory committees. A leadership vacuum exists in the planning area and unless this is assumed by the Government, it is likely that the strategic plans under development will cause tensions between health services, the Government and the State Department of Human Services.

A further implication of this study for Government policy is in the affirmation that the community strongly supports an egalitarian approach to health care. There was some support for discrimination in favour of the young and against the elderly but 73% of interviewees (Table 7.18) considered it important to provide a system that was equally available to all. When asked about restricting access for certain services based on the
lifestyle choices of individuals, 75% of participants believe that people whose behaviour contributes to their illness should receive the same treatment as other people.

This is an extremely positive affirmation of the principles that underlay the Medicare system as recorded at the commencement of this thesis in Chapter 1. It is also consistent with the characteristics of egalitarianism that have been reported in Chapter 2 and earlier in this chapter. A system that provides for “fair equality of opportunity” is a just system and this the data from this study support such a system. Governments may be tempted to adopt the characteristics of other international health systems but on the basis of the results from this study, one criterion that would appear to be inviolate is this notion of egalitarianism.

Rationing of health services is noted to be a problem for the Government and the reasons for this are well understood. It was noted earlier in this chapter that rationing does not have to be contrary to the ideals of an egalitarian system. Rationing will occur when there are insufficient resources to provide all things to all people at all times. This means that one area assumes a higher priority and so long as there is no discrimination within that area of service, the integrity of an egalitarian theory is maintained. Should the Government wish to proceed down the path of priority setting in its services, then this point is extremely relevant. The provision of equal access to a decent minimum range of services is a reasonable objective that can be achieved within an egalitarian framework.

8.7.2 Implications for resource allocation

Governments at both State and Federal levels should note the results of this study that overwhelmingly support the appropriate funding of inpatient facilities, emergency services and aged care services. The funding difficulties experienced by public health facilities were mentioned time and again with the greatest attention being given to acute public hospitals with strong support for additional nurses. While community based services did not rank as high as acute, aged or mental health services, there was strong support for increasing health education in schools and for developing preventive screening and immunisation.
An important outcome from a fiscal perspective was the high number of areas that the participants considered deserved additional resources. Of even greater significance was the willingness of participants to support some form of additional revenue raising by Governments with this being the most common response (Table 7.6). When faced with selecting between quality, timeliness and cost, for the majority of participants, a high quality, timely service took priority over cost (Table 7.14).

The implication for the Commonwealth and State Governments is that the capacity of the community to accept increases in tax revenue is greater if it is associated with providing a high quality health service that treats people in a timely way. The Medicare Levy that is currently used in Australia as a taxation surcharge on personal income tax provides a vehicle for this type of revenue raising policy initiative. So long as there are qualitative and quantitative improvements in the health system as a consequence of raising this levy, then the data from this study suggest the community will receive it reasonably well.

Increasing charges that are levied by individual health services is another option to consider from a policy perspective. The current funding rules agreed upon between the Commonwealth and State Governments preclude charging for inpatient or outpatient care unless the patients elect to be treated as private patients. This restricts the direct patient revenue raising options for health services. While this study indicates support for revenue initiatives, the data highlight a range of revenue raisings, none of which include direct patient contributions. Accordingly, all levels of Government should approach this matter with caution.

The relatively low priority given to community based services in the study reflects the high profile of acute, public hospital care and an understanding of the challenges of caring for the aged. The acute and aged areas were seen to be of greater immediate importance than community based services and this is understandable. However, the trend in a health system of limited resources is that an increasing amount of care is, by necessity, going to be delivered in non-institutional settings and an investment in community based services will be essential to meet that demand.
These data are important signals to health planners and Governments that if the move towards community based services is to be accelerated, then a major effort needs to be made in explaining to the community what this means and the benefits that will accrue as a consequence. Recognition of health education and community based services in Tables 7.4 and 7.5 as areas to be supported suggest that an investment in this area would be supported. However, in a relative sense, community based services are not viewed as being as high a priority as getting the acute and aged care services better resourced and functioning so that waiting times are reduced.

8.7.3 Implications for the community

The development of community participation models provides both an opportunity and a responsibility for the community. As has been discussed previously in this thesis, models of community participation are not new in the health field with Boards of Directors having been a feature of the Victorian health system for over 150 years. However, the new era of community participation that is dawning over the same health system is bringing with it accountability requirements that are both unique and challenging.

Community advisory committees are unique because they have their basis enshrined in legislation and their functions clearly defined in non-statutory guidelines issued by the Victorian Department of Human Services (Victorian Government Department of Human Services, 2000). They are challenging because their advice will be sought on a range of subjects about which many of the participants will have had little, if any experience. It is in this area where there lies a real opportunity to bring the community into the life of the health service.

The risk of creating models of community participation is that they become tokenistic. The community advisory committees and their Boards of Directors within the health service will need to create the right environment for them to effectively function. The community advisory committees should be seen as key players in discussing strategies and initiatives that are important to the health service. They should not be regarded as a legislative impediment to the effective management of the organisation and given enormous amounts of paperwork for their information and feedback.
It is imperative that community advisory committees be given the confidence, support and encouragement of the Board of Directors to carry out the tasks that are mutually agreed between the two bodies. The community advisory committees need to be adequately resourced to explore the boundaries of community participation and this may mean embarking on projects that may seem novel to the more conservative elements in the health service. The role of the community advisory committees may take them into areas that have been traditionally sacrosanct and this will require careful manoeuvring by the community members and support by the Board and its management team.

The responsibility of the community is not to exploit the opportunities created by dominating proceedings with particular sectional interests. The implications of such tactics will be to bring the process into disrepute and will run the risk of prejudicing the entire movement towards engaging the community. It is for this reason that a code of conduct should be developed for members of community advisory committees. Of course there will be times when sectional views are sought and this is a legitimate means of input. The advice that comes to Boards of Directors does not need to be biased by particular interests but should be the product of proper community input based, as far as possible, on objective data collection.

Should the community participation model gain momentum, it can be expected that innovative ways of determining community views will be developed. In a society when it can be determined how many people watch a particular television show by utilising statistically sound sampling techniques, it is not impossible to think that a survey such as has been undertaken in this study could not be more electronically based. Information available to the community will become increasingly accessible in ways that could not be foreseen only five years ago. A more informed community will be able to make better informed decisions about its health system.

The challenge for leaders in health care is to access the technologies to enable more timely and detailed assessments of community opinion so that the way that the health system functions is more in accord with community priorities and expectations. Whether this means that cardiac surgery continues at Barwon Health at its current high levels of quality and timeliness, remains to be seen.
8.8 Concluding Remarks

This thesis has been a journey through the theory and practice of community participation from the perspective of a Chief Executive of a major health care organisation. There has been an endeavour to reflect the notion that a model of distributive justice should be applied in health care decision making and that the best way of determining what that model should be is by seeking the views of the community.

The conclusions drawn from the data place a very practical orientation to the work. The implications for the future of Geelong’s public health services will depend upon how Barwon Health and its Board of Directors wish to pursue the issues identified. They have data not commonly available to health care organisations and this places them in an excellent position to plan their future.

Although this is the end of the thesis, it is not an end point in the subject as there are many opportunities to further explore the data that have been accumulated from both the focus groups and the community survey. This work therefore becomes another small step in the evolution of knowledge about this important subject.

Regardless of how these matters are taken up, the one certainty about this area of health care is that it will always remain subject to political will. As David Hunter (1997) so appropriately puts it, the need to “muddle through elegantly” will always prevail in the realpolitik of health care decision making.
Appendix A
Ethics Approval, Focus Groups Study (REAC)

RESEARCH AND ETHICS ADVISORY COMMITTEE

Secretary REAC
Andrew Love Cancer Centre
The Geelong Hospital
70 Swanston Street
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Barwon Health

ETHICS COMMITTEE APPROVAL STATEMENT

99/71 Mr Capp Identification of the priorities and expectations that the Geelong Community has of its public health care system

Thankyou for submitting your application with the Research and Ethics Advisory Committee.

Full approval was granted on 30/12/1999

In addition any items approved in support of this project are listed below:

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<th>Date Approved</th>
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<td>Research Informed Consent</td>
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I have attached a current list of the REAC Members at the date of the last meeting for your information. The Research and Ethics Advisory Committee is constituted and operates in accordance with the National Health and Medical Research Council’s National Statement on Ethical Conduct in Research Involving Humans (1999).

All Research Projects approved by REAC must comply with the Section “Monitoring”, which requires Human Research Ethics Committees (HRECs) to monitor research projects to which they have given ethical approval in order to ensure that they conform to the protocol approved.

The guidelines detailed below are the current methods and approach used by the HREC to monitor activities of research projects.

2.33 An institution or organisation and its HREC have the responsibility to ensure that the conduct of all research approved by the HREC is monitored by procedures and/or by utilising existing mechanisms within the institution or organisation which will ensure the achievement of the goals for monitoring as determined by the institution or organisation and the HREC.

2.34 The frequency and type of monitoring determined by the HREC should reflect the degree of risk to participants in the research project.

2.35 As a minimum an HREC must require at regular periods, at least annually, reports from principal researchers on matters including:
(a) progress to date or outcomes in the case of completed research
(b) maintenance and security of records
(c) compliance with the approved protocol; and
(d) compliance with any conditions of approval.
2.35 As a minimum an HREC must require at regular periods, at least annually, reports from principal researchers on matters including:
(a) progress to date or outcomes in the case of completed research
(b) maintenance and security of records
(c) compliance with the approved protocol; and
(d) compliance with any conditions of approval

2.36 An HREC may recommend and/or adopt any additional appropriate mechanism for monitoring including random inspections of research sites, data and signed consent forms, and/or interview, with their prior consent, of research participants.

2.37 An HREC shall, as a condition of approval of each protocol, require that researchers immediately report anything which might warrant review of ethical approval of the protocol, including:
(a) Serious or unexpected adverse effects on participants
(b) Proposed changes in the protocol, and
(c) Unforeseen events that might effect continued ethical acceptability of the project

2.38 An HREC shall as a condition of approval of the research proposal, require researchers to inform the HREC, giving reasons, if the research is discontinued before the expected date of completion.

Should you require any further information concerning the Committee's approval of your research or have any concerns regarding the Reporting requirements please contact the REAC secretary, Ms Bemice Lamp on 52267978.

In all future correspondence regarding your study please quote your Project No. and full title of your Research Investigation.

Yours sincerely,

Mr Andrew Hill
Chairperson
Research and Ethics Advisory Committee
Appendix B

Summary of Results Sent to Participants (1)

Brief Summary of Focus Group Findings

Eight focus groups were conducted by Barwon Health with members of the public - four with men, and four with women. Participants came from a range of backgrounds and ages. These notes summarise the findings of the discussions across all of the groups.

What Is Valued About The Public Health Care System

Members of the focus groups were asked what they value most about the public health care system.

- Six of the groups mentioned the quality of the service and / or staff.
- Knowing it is there was mentioned by participants in five of the groups.
- Four groups mentioned the availability of services in Geelong, the fact that it’s free, and the hospice service.
- The Geelong Hospital was specifically referred to by three groups.

Problems With the Public Health Care System

Each group was asked if the public health care system meets their needs, and if not, what do they think are the shortfalls in the system.

- All of the groups mentioned waiting as a problem. The most frequently mentioned types of waiting were for elective surgery, emergency, dental services, and for an appointment with a specialist.
- All groups raised concerns about doctors as an issue. These ranged from stories of specialists being rude and lacking people skills, to doctors not spending enough time with each patient.
- Other problems raised by almost all of the groups included staff shortages, funding shortages, beds closing, and concerns about dental services.
- Five of the groups mentioned a lack of information about what services are available as an issue.
- Concerns about interns working in emergency, shortage of detox places, lack of men’s health services or research, and over-use of the system were raised by two or more groups.
- A range of other matters were raised in only one focus group.

Issues and Priorities

The groups were asked what they saw as a major issue facing the public health care system.

- A lack of staff and / or a lack of money was the most common response.
- A smaller number of groups mentioned the issue of the aging population.
- Some suggested there were “too many chiefs and not enough indians”, waiting times, and aged care.
- Staffing and funding also featured when groups were asked what should be the major priorities of the health system, as well as aged care and mental health.
Funding Alternatives
Each focus group was presented with a series of questions in which they were asked if it is more important to fund one type of activity or another. Most groups found these questions very difficult to answer. There were many comments suggesting that how these questions were answered depended on whether you have a particular person in mind, or think more objectively about the whole community.

Hospital versus community based services.
- Only two of the groups reached a consensus decision on one of these options being more important – both opting for community based services.
- The other groups argued that both types of services are very important.

Cure versus education.
- Three of the groups agreed that education was more important.
- The other five groups commented that both needed to be funded.
- Most time was spent on discussing the pros and cons of educating the public, and the importance of educating people when they are young.

Intensive care for over 80’s versus cancer research.
- Half of the groups agreed that cancer research is more important.
- The other groups could not agree on one option over the other.
- Some suggested that cancer research was very important, but they could not exclude over 80 year olds from intensive care, particularly if they thought about an individual person.

Open heart surgery versus renal care.
- Most groups found this the most difficult of the funding alternatives presented to them.
- Seven groups could not decide on which area was more important. Many commented that they could not answer this question.
- One group argued that open heart surgery was more important, because heart problems are more life threatening.

Mother versus the baby.
In this question, a child was born prematurely and both the baby and the mother needed a lot of care to survive. Each has an equal chance of surviving, but it is only possible to provide one with the necessary care.
- Five of the groups unanimously chose the mother, stating that she could have another child, may have other children to care for, and that there may be long term health problems for a premature baby.
- The other three groups were divided on this question.

Should Everyone Be Treated the Same?
Each focus group was asked if any people should be treated differently because of their age, personal situation, or behaviour.
- The first response to this question in every group except one, was that everyone should be treated the same.
- After some discussion, participants in seven of the groups gave at least some support to the notion of treating people differently if their behaviour had contributed to their health problem, but within each focus group there was often disagreement about this issue.
• At least some participants in all groups indicated that they would give preference to a younger person over an elderly person.

**Do Not Do Everything Possible Sometimes**

Participants were asked if there are times when medical professionals should not do everything they can to prevent death. It was explained that this was not asking about euthanasia, or assisting death, but not doing everything possible to prevent a patient dying when they were very ill.

• In some of the groups individual participants expressed an initial response that everything possible should always be done, but the discussion in each group focussed on when it is preferable to allow someone to die, frequently with examples from personal experience.

• While each group was not asked to make a consensus decision, the overall view in each group was that there are times when everything possible should not be done. The importance of medical professionals consulting with the patient and / or the family was stressed.

• There were several comments about this being a hard question.

**Who Should Make Decisions**

Each group was asked who should determine the priorities of the public health care system, or who should make the “big picture” decisions.

• The common theme during this part of the focus groups was that the people who make the decisions about the public health care system should have experience with that system.

• This was the reason given why health professionals or users of the services should be involved in the process, and why politicians should not be responsible for decisions.

• When specifically asked about members of the public being involved in making “big picture” decisions, most groups thought that this was a good idea, although some individuals were not certain that this would work.

**Comments From Individuals**

A small number of individual members of the public also contributed to this project. They raised some areas of concern which did not emerge from the focus groups: the need for increased suicide prevention and counselling services; the high number of adverse events in hospitals; the effect of environmental hazards on health; and the need for interpreters for people from non-English speaking backgrounds. It was suggested that Barwon Health should provide more mental health programs and promote these to the public, and provide an information centre or helpline to assist the public in researching health issues.
Appendix C

Blank Consent Form

BARWON HEALTH

RESEARCH INFORMED CONSENT FORM

Project Title: Identification of the priorities and expectations that the Geelong community has of its public health care system.

Principal Investigator  Stan Capp

Co-investigator(s)  Dr Sally Savage

Subject's name: ........................................................................................................

1. I, the undersigned ........................................................................................................
   have been asked to participate in a research study titled: Identification of the priorities and
   expectations that the Geelong community has of its public health care system
   under the direction of Mr Stan Capp.

2. I understand that the purpose of the study is to identify the priorities and expectations that the Geelong
   community has of its public health care system; to determine if there is a common view on the
   attributes of a just health system; and to consider a method of utilising the data in the determination of
   health care priority setting in Barwon Health.

3. I understand that the study will involve participating in a focus group for 1.5 hours with other people to
   discuss these matters, and that this discussion will be tape recorded.

4. I understand that this process does not involve any physical risks or discomforts but I may be
   challenged to contemplate choices and make value judgments about issues that may be personally
   challenging or distressing.

5. The details of the study and the purpose of the study have been fully explained to me by: Mr Capp or
   Dr Savage.

   I have read and understood the information sheet concerning the study which has been supplied to me.

   I have been given the opportunity to ask questions regarding the study and any questions that I have
   asked were answered to my satisfaction.

   I have been given the opportunity to have a family member or a friend available while the project was
   explained to me.

6. I authorise Stan Capp to preserve, use or publish the results of this study, provided my identity is not
   revealed to other persons.

7. I understand that I may not receive a direct benefit from the study.

8. I understand that my involvement in this study will not affect my relationship with my medical advisors
   in the management of my health. I understand that my participation in this study may be terminated at
   any time upon my wishes or at the discretion of Stan Capp and this will in no way affect my subsequent
   medical care.
9. I have been given/offered a copy of this consent form.

10. I HEREBY VOLUNTARILY CONSENT AND OFFER TO TAKE PART IN THIS STUDY.

..........................................................  ........../........../.............
Signature of SUBJECT                            Date

..........................................................  ........../........../.............
Signature of WITNESS                            Date

..........................................................
Status of WITNESS

DECLARATION BY INVESTIGATOR

I hereby declare that I have given the subject all necessary information regarding his/her involvement in the study and believe he/she has understood it. He/she will also be informed of any changes in the study. I declare that the abovenamed subject freely gave consent to participate in this study.

..........................................................  ........../........../.............
Signature of INVESTIGATOR                       Date

DECLARATION BY WITNESS  (Delete if not applicable)

I,
hereby declare that I am acquainted with both (subject) ....................................................
and (investigator) ..........................................................
and certify that the signatures on this declaration are those of the subject and the investigator.
I further certify that the investigator has advised the subject of the purpose and risks of the project.

..........................................................  ........../........../.............  ..........................................................
Signature of WITNESS                            Date                                Status of WITNESS
Appendix D

Ethics Approval, Survey Questionnaire Study (REAC)

RESEARCH AND ETHICS ADVISORY COMMITTEE

Secretary REAC
Andrew Love Cancer Centre
The Geelong Hospital
70 Swanston Street
GEELONG 3215

Telephone: 03 5226 7978
Facsimile: 03 5226 7857
e-mail: BERNICE@BarwonHealth.org.au

ETHICS COMMITTEE APPROVAL STATEMENT

99/71_E1 Mr Capp
Identification of the priorities and expectations that the Geelong community has of its public health system

Thankyou for submitting your application with the Research and Ethics Advisory Committee.

Full approval was granted on 16/05/2000

In addition any items approved in support of this project are listed below:

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<th>Item ID</th>
<th>Additional Information</th>
<th>Document Date</th>
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<tr>
<td>16/05/2000</td>
<td>Interview schedule</td>
<td>Version 1: undated</td>
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I have attached a current list of the REAC Members at the date of the last meeting for your information. The Research and Ethics Advisory Committee is constituted and operates in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Research involving Humans (1999).

All Research Projects approved by REAC must comply with the Section “Monitoring”, which requires Human Research Ethics Committees (HRECs) to monitor research projects to which they have given ethical approval in order to ensure that they conform to the protocol approved.

The guidelines detailed below are the current methods and approach used by the REAC to monitor activities of research projects.

2.33 An institution or organisation and its HREC have the responsibility to ensure that the conduct of all research approved by the HREAC is monitored by procedures and/or by utilising existing mechanisms within the institution or organisation which will ensure the achievement of the goals for monitoring as determined by the institution or organisation and the HREC.

2.34 The frequency and type of monitoring determined by the HREC should reflect the degree of risk to participants in the research project.
Ethics Approval, Survey Questionnaire Study (REAC) (Cont.)

2.35 As a minimum an HREC must require at regular periods, at least annually, reports from principal researchers on matters including:
(a) progress to date or outcomes in the case of completed research
(b) maintenance and security of records
(c) compliance with the approved protocol; and
(d) compliance with any conditions of approval

2.36 An HREC may recommend and/or adopt any additional appropriate mechanism for monitoring including random inspections of research sites, data and signed consent forms, and/or interview, with their prior consent, of research participants.

2.37 An HREC shall, as a condition of approval of each protocol, require that researchers immediately report anything which might warrant review of ethical approval of the protocol, including:
(a) Serious or unexpected adverse effects on participants
(b) Proposed changes in the protocol, and
(c) Unforseen events that might effect continued ethical acceptability of the project

2.38 An HREC shall as a condition of approval of the research proposal, require researchers to inform the HREC, giving reasons, if the research is discontinued before the expected date of completion.

Should you require any further information concerning the Committee's approval of your research or have any concerns regarding the Reporting requirements please contact the REAC secretary, Ms Bernice Lamp on 52267978.

In all future correspondence regarding your study please quote your Project No. and full title of your Research Investigation.

Yours sincerely,

Signature Redacted by Library

Mr Andrew Hill
Chairperson
Research and Ethics Advisory Committee
Appendix E
Ethics Approval, Survey Questionnaire Study (DUEC)

Research Services
Office of the Pro Vice-Chancellor (Research) (Burwood Campus)

MEMORANDUM

TO:       Mr Stan Capp  cc: Assoc Prof Val Clarke
          Psychology                Geelong
FROM:    Secretary, Deakin University Ethics Committee (DUEC)
DATE:    13 April 2000
SUBJECT: PROJECT: EC 48-2000  (Please quote this project number in future communication.)

IDENTIFICATION OF THE PRIORITIES AND EXPECTATIONS THAT THE GEELONG COMMUNITY HAS OF ITS PUBLIC HEALTH CARE SYSTEM

The above project was considered at DUEC Meeting 2/00 held on 10 April 2000. The Ethics Committee decision is as follows.

THAT THIS JOINT BARWON HEALTH-DEAKIN PROJECT AS UNDERTAKEN BY MR STAN CAPP, UNDER THE SUPERVISION OF ASSOC PROF VAL CLARKE, PSYCHOLOGY, BE APPROVED FROM 11 APRIL 2000 TO 31 DECEMBER 2000 SUBJECT TO EVIDENCE OF CLEARANCE FROM BARWON HEALTH.

Standard ethics clearance has been given for the above project, subject to evidence of ethics clearance by Barwon Health.

In arriving at its's decision the Committee considered the revised instruments submitted on your behalf by Dr Sally Savage. A photocopy of the ethics clearance given by Epworth Hospital's ethics committee will need to be forwarded to the DUEC Secretary as soon as possible for the record.

Keith Wilkins
Secretary, DUEC
Email: keithwil@deakin.edu.au

Signature Redacted by Library
Appendix F

Summary of Results Sent to Participants (2)

**Brief Summary of Telephone Interviews Findings**

These notes summarise the main findings from the telephone interviews recently conducted with members of the public in the Geelong area.

**Participants**
- A total of 400 people from the Geelong area were interviewed by telephone.
- Half of those interviewed were men and half were women. Half were aged between 18 and 40 years, and half were aged 41 years or more.
- Telephone numbers were randomly selected from an electronic version of the Geelong telephone directory.
- 30% of people contacted agreed to take part in the 20 minute interview.

**Does the Public Health Care System Meet Your Needs?**
- Most people said that the public health care system meets their needs very well or quite well.

- Most people reported that doctors do listen enough to their problem, communicate with them clearly, and that specialists treat them with respect.

**Problems in the Public Health Care System**
- The shortfalls in the public health care system most often mentioned were waiting times, especially waiting for elective surgery, staff or funding shortages, and beds closing.

- Having to wait too long for treatment, and staff being too busy were rated as a serious problem by most people.

**What is Valued about the Public Health Care System?**
- When asked what they value most about the public health care system, the things mentioned by the most people were the fact that it is free, that it is there when you need it, that services are available in Geelong, and that services are available for everyone.

**What is Most Important for the Public Health Care System to Provide**
- The services which were most often mentioned as important for the public health care system to provide were hospitals or more beds, emergency services, aged care and more doctors.

- A series of questions was used to rate the importance of various health services. Accident and emergency services were given the highest rating, followed by special care and pain relief for people who are dying, and preventive screening and immunisations.
• A series of alternatives was presented - many people found these questions difficult to answer. Most people thought it was more important to spend money on hospitals rather than community based services, and cancer research rather than intensive care units for people over 80. More people thought it was important to save a mother who needed a lot of care rather than a premature baby who needed a lot of care, however many people said they could not answer this question. Equal numbers of people said it was most important to spend money on curing illness or educating the public about health risks.

• Responses to other alternatives indicated that most people think everyone should be treated the same in the health system, even if they have contributed to their own illness.

• When thinking about the public health care system as a whole, almost three-quarters of people interviewed thought that it was most important for it to be equally available to all.

Where Should More Money be Spent?
• When asked where they thought more money should be spent, hospitals were mentioned by most people, followed by more staff and aged care services.

• When asked if a number of particular services should receive more funding, the areas which most people thought should get more funding were employing additional nurses, health education in schools, and mental health.

Who Should Make the Decisions?
• When asked a series of questions about who should make the decisions about the public health care system, most people did not want politicians or administrators, or medical professionals, to make all the decisions. There was strong support for using a survey like this one in planning health services. The majority agreed that having a group of people from the community contribute to making decisions was a good idea.

• Most people agreed that patients who are able to understand should always have some say in decisions about their medical treatment, and that the patient’s quality of life should be considered in deciding whether to use lifesaving treatment or technology.
Appendix G

Interview Schedule

The community's views of the public health care system.
Most questions ask about the public health care system – which are those areas of health care that are funded directly by Government (compared to the private sector). There are no right or wrong answers to these questions.

1. What do you value most about the public health care system? (Tick any response given) (DON'T READ OUT)
   □ It's free / Medicare
   □ It's there when needed
   □ Quality of service or staff
   □ It's competent
   □ Availability (in Geelong)
   □ Community based services
   □ Cancer care
   □ Choose own doctor
   □ Nothing / No response
   □ Other
   □ Geelong Hospital
   □ Grace McKellar
   □ Aged care in general
   □ Quick response
   □ Hospital in the home
   □ Emergency care
   □ Hospice service
   □ Available for everyone

2. How well does the public health system meet your needs? (READ RESPONSES)
   □ Extremely well
   □ Very well
   □ Quite well
   □ Not very well
   □ Not at all
   □ Can't say

3. What are the shortfalls in the public health care system? (DON'T READ OUT)
   □ Waiting (elective surgery)
   □ Waiting (GPs)
   □ Waiting (Specialist)
   □ Waiting (Dental)
   □ Waiting (Emergency)
   □ Waiting (Other)
   □ Not enough detox places
   □ Beds closing
   □ Men's health limited
   □ Dental services probs
   □ Over-use of system
   □ Need more interpreters
   □ Lack of choice
   □ Gap between rich and poor
   □ Nothing / No response
   □ Other
   □ Doctors are rude
   □ Doctors too quick
   □ Doctors communication
   □ Specialists rude
   □ Specialists too quick
   □ Specialists communication
   □ Nurses overworked
   □ Staff overworked
   □ Staff shortages
   □ Funding shortages
   □ Beds closing
   □ Interns in emergency
   □ Lack of coordination
   □ Lack of information
4. What services are most important for the public health system to provide? (DON'T READ OUT)

☐ Aged care
☐ After care services
☐ Ambulances
☐ Ancillary services
☐ Cheap / free medication
☐ Children’s specialists
☐ Community health centres
☐ Dental services
☐ Detox places / Drug & alcohol
☐ Disabled services
☐ Doctors / more doctors
☐ Education
☐ Elective surgery
☐ Emergency services
☐ Free health care
☐ Home nursing

☐ Hospice
☐ Hospitals / More beds
☐ Immunisation
☐ Information
☐ Maternal / child health
☐ Mental health services
☐ More staff
☐ Prevention
☐ Research
☐ Research - cancer
☐ Rural health services
☐ Screening tests
☐ Shorter waiting times
☐ Sight / hearing services
☐ Specialists / More spec
☐ 24 hour access to GPs

☐ Nothing / No response

☐ Other

5. If more money was available for public health services, where do you think it should be spent? (DON’T READ OUT)

☐ Aged care
☐ After care services
☐ Ambulances
☐ Ancillary services
☐ Cheap / free medication
☐ Children’s specialists
☐ Community health centres
☐ Dental services
☐ Detox places / Drug & alcohol
☐ Disabled services
☐ Doctors / more doctors
☐ Education
☐ Elective surgery
☐ Emergency services
☐ Free health care
☐ Home nursing
☐ No need to spend more money
☐ Nothing / No response

☐ Hospice
☐ Hospitals / More beds
☐ Immunisation
☐ Information
☐ Maternal / child health
☐ Mental health services
☐ More staff
☐ Prevention
☐ Research
☐ Research - cancer
☐ Rural health services
☐ Screening tests
☐ Shorter waiting times
☐ Sight / hearing services
☐ Specialists / More spec
☐ 24 hour access to GPs

☐ Other
6. Using a scale from 0 to 10, with 0 being Poor, and 10 being Excellent:
   Overall, how would you rate Geelong’s public health care system?
The scale 0 to 10 - 0 is Poor, and 10 is Excellent.
   (CIRCLE THE APPROPRIATE NUMBER FOR EACH)

   0  1  2  3  4  5  6  7  8  9  10
   Poor  Excellent
   □ Can’t say

7. Overall, how would you rate Victoria’s public health care system?
   0  1  2  3  4  5  6  7  8  9  10
   Poor  Excellent
   □ Can’t say

8. Overall, how would you rate The Geelong Hospital?
   0  1  2  3  4  5  6  7  8  9  10
   Poor  Excellent
   □ Can’t say

9. Overall, how would you rate the Grace McKellar Centre, Geelong’s rehab and aged care facility?
   0  1  2  3  4  5  6  7  8  9  10
   Poor  Excellent
   □ Can’t say

10. Overall, how would you rate the community based services available in this area? (E.g. community health centres, drug and alcohol services)
    0  1  2  3  4  5  6  7  8  9  10
    Poor  Excellent
    □ Can’t say

11. I’m going to read out two things. Thinking about health services, I want you to
tell me which is most important to you:

   (a)  □ Getting the service quickly  OR
        □ Getting good quality service?

   (b)  □ Getting the service quickly  OR
        □ Getting the service for free?

   (c)  □ Getting good quality service  OR
        □ Getting the service for free?
Using a different scale now, from 0 to 10, with 0 being Not at all important, and 10 being Extremely important, how important do you think is each of the following? (CIRCLE THE APPROPRIATE NUMBER FOR EACH)

12. Hospital based services.
   
   0 1 2 3 4 5 6 7 8 9 10
   Not at all important
   Extremely important

13. Aged care services.
   
   0 1 2 3 4 5 6 7 8 9 10
   Not at all important
   Extremely important

14. After-care services for patients leaving hospital.
   
   0 1 2 3 4 5 6 7 8 9 10
   Not at all important
   Extremely important

15. Health education services to help people live healthy lives.
   
   0 1 2 3 4 5 6 7 8 9 10
   Not at all important
   Extremely important

16. Drug and alcohol services.
   
   0 1 2 3 4 5 6 7 8 9 10
   Not at all important
   Extremely important

17. Special care and pain relief for people who are dying.
   
   0 1 2 3 4 5 6 7 8 9 10
   Not at all important
   Extremely important

18. Surgery, such as hip replacement, to help people carry out everyday tasks.
   
   0 1 2 3 4 5 6 7 8 9 10
   Not at all important
   Extremely important
19. Long stay hospital care for elderly people.

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20. Accident and emergency services.

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21. Services for people with mental illness.

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22. Preventive screening services and immunisations.

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23. Free dental services.

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I'm going to read you a list of things that some people have had a problem with in the health system. For each one, I want you to tell me whether you think this is a problem.

24. Having to wait too long for treatment. Is this a: (READ RESPONSES)

- ☐ Serious problem
- ☐ Mild problem
- ☐ Not a problem

(DON'T READ OUT)

☐ Can't say

25. Staff are too busy. Is this a: (READ RESPONSES)

- ☐ Serious problem
- ☐ Mild problem
- ☐ Not a problem

☐ Can't say
26. Having to wait too long to get an appointment. Is this a: (READ RESPONSES)

3 □ Serious problem
2 □ Mild problem
1 □ Not a problem
0 □ Can’t say

27. Not knowing what services are available. Is this a: (READ RESPONSES)

3 □ Serious problem
2 □ Mild problem
1 □ Not a problem
0 □ Can’t say

28. Needing an interpreter and not being offered one. Is this a: (READ RESPONSES)

3 □ Serious problem
2 □ Mild problem
1 □ Not a problem
0 □ Can’t say

29. Not enough after-care services for patients discharged from hospital. Is this a: (READ RESPONSES)

3 □ Serious problem
2 □ Mild problem
1 □ Not a problem
0 □ Can’t say

30. Being discharged from hospital too early. Is this a: (READ RESPONSES)

3 □ Serious problem
2 □ Mild problem
1 □ Not a problem
0 □ Can’t say

31. I’m going to read out four things to you. Thinking about the public health care system as a whole, which one of these things do you think is the most important? (TICK ONE BOX)

4 □ Helping the most people OR
3 □ Being equally available to all OR
2 □ Providing the services which the community has decided it wants OR
1 □ Providing services according to one’s ability to pay.
0 □ Can’t say
32. Do you think it is more important to spend money on:

☐ Hospitals  OR

☐ Community based services?

☐ Can't say

Why do you say that? (DON'T READ OUT)

☐ Both are important, both need funding

☐ Hospitals need more money now

☐ People need hospitals when illness is serious

☐ Everything people need is in the hospital

☐ Community based is first contact people have with health services

☐ More community based services might reduce need for hospital

☐ Other ____________________________

33. Is it more important to spend money on:

☐ Curing illness  OR

☐ Educating the public about health risks?

☐ Can't say

Why do you say that? (DON'T READ OUT)

☐ Both are important, both need funding

☐ You have to cure / treat sick people

☐ Can only do so much with education

☐ If educate, may avoid illness

☐ Prevention / education is better than cure

☐ Educate young people

☐ Other ____________________________

34. Is it more important to spend money on:

☐ Intensive care units for people over 80  OR

☐ Cancer research?

☐ Can’t say
Why do you say that? (DON'T READ OUT)

[ ] Both are important, both need funding
[ ] Can't refuse treatment based on age
[ ] Over 80's entitled to good quality of life
[ ] Over 80's have had a good innings
[ ] People over 80 would say look after younger people
[ ] Previous / personal experience
[ ] Cancer research needs more money
[ ] Cancer claims too many lives
[ ] Cancer affects everyone
[ ] Other __________________________

35. Is it more important to spend money on:
   [ ] Saving a premature baby who needs lots of care  OR
   [ ] Saving the mother, who also needs lots of care?
   [ ] Can't say

Why do you say that?

(DON'T READ OUT)

[ ] Can't choose between people
[ ] Baby has it's whole life ahead of it
[ ] Mother may have other children to care for
[ ] Mother is established member of family / community
[ ] Mother could have other children later
[ ] Premature baby may have long term health problems
[ ] Baby without mother is at a big disadvantage
[ ] Other __________________________

36. Some people's behaviour contributes to their illness, for example people who smoke or drink excessively. Do you think that these people should:
   [ ] Have to wait longer for treatment  OR
   [ ] Should be treated the same as other people in the health system?
   [ ] Can't say

37. Dealing with a situation where there is something that cannot be available to everyone, for example an organ transplant where there is only one organ, do you think:
   [ ] A young person should take priority over an older person  OR
   [ ] Everyone should be treated equally regardless of their age?
   [ ] Can't say
38. When deciding which services to put money into, the most money should be put into:
   2☐ Services which help the most people  OR
   1☐ Services which help the sickest people.
   0☐ Can’t say

39. Premature babies should be given intensive care:
   2☐ Only when they have a very good chance of surviving  OR
   1☐ Regardless of their chances of survival.
   0☐ Can’t say

When you’re answering the next questions, I want you to assume that there is no extra money available for health services. Therefore, if you think that more money should be put into some of the health services I ask you about, assume that the money would have to come from somewhere else.
I’m going to read you some statements, and I want you to say if you agree or disagree with each one.

40.* More funds should be put into mental health services. Do you: (READ RESPONSES)
   5☐ Strongly agree
   4☐ Agree
   3☐ Neither agree nor disagree
   2☐ Disagree
   1☐ Strongly disagree

41.* More funds should be put into suicide prevention services. Do you: (READ RESPONSES)
   5☐ Strongly agree
   4☐ Agree
   3☐ Neither agree nor disagree
   2☐ Disagree
   1☐ Strongly disagree

42. Spending money on health education is a waste of money. Do you: (READ RESPONSES)
   5☐ Strongly agree
   4☐ Agree
   3☐ Neither agree nor disagree
   2☐ Disagree
   1☐ Strongly disagree
43.* More funds should be put into employing additional nurses. Do you: (READ RESPONSES)

[ ] Strongly agree
[ ] Agree
[ ] Neither agree nor disagree
[ ] Disagree
[ ] Strongly disagree

44. There are enough services in the Geelong area to help people get off drugs or alcohol. Do you: (READ RESPONSES)

[ ] Strongly agree
[ ] Agree
[ ] Neither agree nor disagree
[ ] Disagree
[ ] Strongly disagree

45.* There should be more men’s health services available. Do you: (READ RESPONSES)

[ ] Strongly agree
[ ] Agree
[ ] Neither agree nor disagree
[ ] Disagree
[ ] Strongly disagree

46.* There should be more health education in schools. Do you: (READ RESPONSES)

[ ] Strongly agree
[ ] Agree
[ ] Neither agree nor disagree
[ ] Disagree
[ ] Strongly disagree

47. If more money was spent on community based services, fewer people would need to go to hospital. Do you: (READ RESPONSES)

[ ] Strongly agree
[ ] Agree
[ ] Neither agree nor disagree
[ ] Disagree
[ ] Strongly disagree
IF participant agreed that there should be more money spent in several areas (questions marked *), ASK:

48. You’ve agreed that more money should be spent on several health services. Given that there’s limited money available, where do you think the extra money should come from? (Prompt, do you think other services should be cut, if so which ones, or do you think taxes should be increased?)

☐ Increase taxes (everyone)
☐ Increase taxes (specified wealthy only)
☐ Increase Medicare levy (everyone)
☐ Increase Medicare levy (specified wealthy only)

☐ Cut spending on ______________________________

☐ Reduce other health services ______________________________

☐ Other ______________________________

For the next three questions I’m going to ask you how often this happens.

49. Do doctors listen enough to your problem? (READ RESPONSES)

☐ All of the time
☐ Most of the time
☐ Some of the time
☐ None of the time ☐ Can’t say

50. Do specialists treat you with respect? (READ RESPONSES)

☐ All of the time
☐ Most of the time
☐ Some of the time
☐ None of the time ☐ Can’t say

51. Does your doctor communicate with you clearly? (READ RESPONSES)

☐ All of the time
☐ Most of the time
☐ Some of the time
☐ None of the time ☐ Can’t say
The next questions ask how much you agree with each statement.

52. Patients who are able to understand should always have some say in decisions about their medical treatment. Do you: (READ RESPONSES)

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree

53. When a person is extremely ill, and unlikely to live much longer no matter what treatment they have, doctors should always go ahead with any treatment that is possible. Do you: (READ RESPONSES)

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree

54. As a society, we need to learn to be more accepting of death. Do you: (READ RESPONSES)

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree

55. The patient’s quality of life should be considered in deciding whether to use lifesaving treatment or technology. Do you: (READ RESPONSES)

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree

56. I know what health services are available in my area. Do you: (READ RESPONSES)

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
I’m going to ask you some questions now about who should make decisions about the health system. The sorts of decisions I’ve been asking you about could be made by medical professionals, by administrators, or by members of the public. I’ll read out some statements, and ask if you agree with each.

57. Medical professionals should make all the decisions about the health care system. Do you: (READ ANSWERS)

☑ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree

58. Politicians and administrators should make all the decisions about the health care system. Do you: (READ ANSWERS)

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree

59. Surveys of the public’s opinions like this one should be used in planning health services. Do you: (READ ANSWERS)

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree

60. Some countries have a group of people from the community who contribute to making decisions about major issues facing the public health care system. Do you agree that that is a good idea? Do you: (READ ANSWERS)

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
61. If members of the community are involved in making decisions, only well educated, articulate people should represent the community. Do you: (READ ANSWERS)

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree

62. If members of the community are involved in making decisions, only people who use the public health care system should represent the community. Do you: (READ ANSWERS)

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree

Now I would like to ask some general background questions about yourself.

1. How would you rate your health in general? Would you say it is: (READ ANSWERS)

☐ Excellent
☐ Very good
☐ Good
☐ Poor
☐ Very poor

2. Do you have any longstanding illness or infirmity, anything that has troubled you over a period of time or that is likely to affect you over a period of time?

☐ Yes
☐ No

3. Have you consulted a General Practitioner in the last 12 months?

☐ Yes
☐ No

If Yes, How many times?

☐ More than 12 times
☐ 7 to 12 times
☐ 3 to 6 times
☐ Twice
☐ Once
4. Does your General Practitioner bulk bill?
   □ Yes
   □ No
   □ Can’t say

5. (Interviewer complete:) Sex
   □ Male
   □ Female

6. What is your age?
   □ 80 years or more
   □ 71 to 79 years
   □ 61 to 70 years
   □ 51 to 60 years
   □ 41 to 50 years
   □ 31 to 40 years
   □ 18 to 30 years

7. What is your marital status?
   □ Married
   □ De facto
   □ Widowed
   □ Divorced
   □ Separated, not divorced
   □ Never married
   □ Not stated

8. Do you have any children?
   □ Yes
   □ No

9. What is the highest level of formal education that you have completed?
   □ Higher degree
   □ Tertiary – diploma or degree
   □ Vocational qualification
   □ Completed Year 12 or equivalent
   □ Some secondary
   □ Primary only
   □ Not stated
10. Do you smoke cigarettes?
   
   2  Yes
   1  No

11. Do you have private health insurance?
   
   2  Yes
   1  No

12. What is your current employment status?
   
   8  Employed full time
   7  Employed part time or casual
   6  Unemployed, seeking work
   5  Home duties
   4  Retired
   3  Disability pension
   2  Student
   1  Other

13. Do you, or have you ever, worked as a health professional?
   
   2  Yes
   1  No

14. What country were you born in?
   
   2  Australia
   1  Other

15. What language do you speak at home?
   
   2  English
   1  Other

16. What is your postcode?
   

THANK PARTICIPANT FOR THEIR HELP
OFFER COPY OF SUMMARY
Appendix H

Differences Across Sex, Age and SES Groups

The following tables present the results of a series of chi-square tests and t-tests comparing men and women, participants aged 18 to 40 with those aged 41 and over, and participants living in upper SES suburbs with those living in lower SES suburbs. Chi-square values or independent samples t-test values are only presented for comparisons reaching statistical significance at an alpha level of 0.01 as 0.05 may be misleading due to the large number of comparisons being made. Only responses to open questions mentioned by 10% or more of participants are included in these tables.

These tests are non-directional, so two-tail levels of probability are reported. The confidence in the finding is increased as the probability of the finding occurring by chance is decreased, so that a p value of 0.001 indicates that there is less likelihood of the result occurring by chance that does a p value of 0.01. The tables in Appendix A indicate the variables for which there is a significant difference, state the chi-square or t-test value and provide the p value. The “more” and “less” in the table indicate the direction of that difference.
Table F1  Comparisons - Most Important Services and Where Should More Money be Spent

<table>
<thead>
<tr>
<th>Item / Response</th>
<th>Sex</th>
<th>Age</th>
<th>SES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males compared to</td>
<td>Older compared to</td>
<td>Upper compared to</td>
</tr>
<tr>
<td></td>
<td>females</td>
<td>younger</td>
<td>lower</td>
</tr>
<tr>
<td></td>
<td>Chi-Square (1, N = 400)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Most important for public health care system to provide (% mentioned)*

- Hospitals / More beds (28%) 7.7 * More - 7.7 * Less
- Emergency services (19%) - - -
- Aged care (15%) - - -
- Doctors / More doctors (12%) - - -
- Shorter waiting times (10%) - - 7.4 * Less

*Spend more money on (% mentioned)*

- Hospitals / more beds (42%) 6.4 * More - -
- More staff (21%) - - -
- Aged care (17%) - - -
- Shorter waiting times (12%) - - 14.1 ** Less

*p < .01  ** p < .001
<table>
<thead>
<tr>
<th>Item / Response</th>
<th>Sex</th>
<th>Age</th>
<th>SES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males compared to females</td>
<td>Older compared to younger</td>
<td>Upper compared to lower</td>
</tr>
<tr>
<td></td>
<td>t-tests</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Ratings from Not at all Important to</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Extremely Important – difference in means</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(n providing a rating)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accident and emergency services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(n = 400, df = 398)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Special care and pain relief for the dying</td>
<td>3.4 ** Less</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>(n = 397, df = 395)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preventive screening and immunisations</td>
<td>4.3 ** Less</td>
<td>-</td>
<td>3.3 ** Less</td>
</tr>
<tr>
<td>(n = 398, df = 396)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aged care services</td>
<td>2.9 * Less</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>(n = 397, df = 395)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Services for people with mental illness</td>
<td>3.8 ** Less</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>(n = 393, df = 391)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery such as hip replacement surgery</td>
<td>3.5 ** Less</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>(n = 397, df = 395)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital based services</td>
<td>-</td>
<td>-</td>
<td>4.2 ** Less</td>
</tr>
<tr>
<td>(n = 398, df = 396)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>After-care services for patients</td>
<td>4.6 ** Less</td>
<td>-3.1 * More</td>
<td>-</td>
</tr>
<tr>
<td>(n = 400, df = 398)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Long stay hospital care for elderly people</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>(n = 392, df = 390)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health education services</td>
<td>3.0 * Less</td>
<td>-2.5 * More</td>
<td>-</td>
</tr>
<tr>
<td>(n = 399, df = 397)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drug and alcohol services</td>
<td>3.2 * Less</td>
<td>-</td>
<td>-2.6 * More</td>
</tr>
<tr>
<td>(n = 391, df = 389)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Free dental services</td>
<td>2.5 * Less</td>
<td>-2.5* More</td>
<td>4.1 ** Less</td>
</tr>
<tr>
<td>(n = 399, df = 397)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* p < .01    ** p < .001
Table F3  Comparisons - Additional Funds for Particular Services, and Where Extra Money Should Come From

<table>
<thead>
<tr>
<th>Item / Response</th>
<th>Sex</th>
<th>Age</th>
<th>SES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males compared to females</td>
<td>Older compared to younger</td>
<td>Upper compared to lower</td>
</tr>
<tr>
<td>Agreement or Disagreement with each statement – difference in means</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More funds should be put into employing additional nurses</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>There should be more health education in schools</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>More funds should be put into mental health</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>More funds should be put into suicide prevention</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>There should be more men’s health services available</td>
<td>3.0 * Less</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>If more money was spent on CBS, fewer people would need to go to hospital</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>There are enough services in the Geelong area to help people get of drugs or alcohol</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Spending money on health education is a waste of money</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

**Chi-square (1, N = 400)**

Where should the extra money come from? (% mentioned)

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase taxes for everyone (16%)</td>
<td>-</td>
<td>-</td>
<td>6.8 * Less</td>
</tr>
<tr>
<td>Don’t know (14%)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Cut politician’s pay, travelling, perks (13%)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

*p < .01     **p < .001
<table>
<thead>
<tr>
<th>Item / Response</th>
<th>Sex</th>
<th>Age</th>
<th>SES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males compared to females</td>
<td>Older compared to younger</td>
<td>Upper compared to lower</td>
</tr>
<tr>
<td>Community based services OR Hospitals</td>
<td>7.1 * More</td>
<td>-</td>
<td>13.6 ** Less</td>
</tr>
<tr>
<td>Hospitals chosen (60%)</td>
<td>-</td>
<td>-</td>
<td>7.2 * Less</td>
</tr>
<tr>
<td>Curing illness OR Educating the public about health risks</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Curing illness chosen (37%)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Cancer research OR Intensive care units for people over 80?</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Cancer research chosen (72%)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Saving a mother who needs lots of care OR Saving a premature baby - needs lots of care</td>
<td>-</td>
<td>6.8 * More</td>
<td>-</td>
</tr>
<tr>
<td>Saving a mother chosen (50%)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

* p < .01  ** p < .001
### Table F5  Comparisons – How Well are Needs Met and Shortfalls in the Public Health Care System

<table>
<thead>
<tr>
<th>Item / Response</th>
<th>Sex Males compared to females</th>
<th>Sex Older compared to younger</th>
<th>Sex Upper compared to lower</th>
<th>Chi-Square (1, N = 400)</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>How well does public health care system meet your needs?</em></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Responded either Extremely Well or Very Well (37%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Shortfalls in the public health care system (% mentioned)</em></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Waiting (elect. surgery) (34%)</td>
<td>-</td>
<td>-</td>
<td></td>
<td>7.5 * Less</td>
</tr>
<tr>
<td>Waiting (in general) (15%)</td>
<td>-</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff shortages (15%)</td>
<td>-</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nothing / no response (15%)</td>
<td>-</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Waiting (emergency) (13%)</td>
<td>-</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Waiting (specialist) (12%)</td>
<td>-</td>
<td>-</td>
<td></td>
<td>17.6 ** Less</td>
</tr>
<tr>
<td>Funding shortages (11%)</td>
<td>-</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Waiting (GPs) (10%)</td>
<td>-</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beds closing (10%)</td>
<td>-</td>
<td>-</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* p < .01   ** p < .001
<table>
<thead>
<tr>
<th>Item / Response</th>
<th>Sex</th>
<th>Age</th>
<th>SES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males compared to females</td>
<td>Older compared to younger</td>
<td>Upper compared to lower</td>
</tr>
<tr>
<td><strong>t-tests</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problems rated from Not a Problem to Serious Problem – difference in means (n providing a rating)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having to wait too long for treatment (n = 390, df = 388)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Staff are too busy (n = 391, df = 389)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Being discharged from hospital too early (n = 384, df = 382)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Having to wait too long to get an appointment (n = 387, df = 385)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Needing an interpreter and not being offered one (n = 317, df = 315)</td>
<td>-</td>
<td>3.1 * More</td>
<td>-</td>
</tr>
<tr>
<td>Not knowing what services are available (n = 397, df = 395)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Not enough after-care services for patients discharged from hospital (n = 372, df = 370)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Ratings from Poor to Excellent – difference in means (n providing a rating)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grace McKellar Centre (n = 230, df = 228)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>The Geelong Hospital (n = 371, df = 369)</td>
<td>-2.5 * More</td>
<td>-2.7 * More</td>
<td>-</td>
</tr>
<tr>
<td>Community based services in this area (n = 322, df = 320)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Geelong’s public health care system (n = 380, df = 378)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Victoria’s public health care system (n = 320, df = 318)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

*p < .01  ** p < .001
Table F7  Comparisons - Interactions With Health Professionals and Responses to Various Statements

<table>
<thead>
<tr>
<th>Item / Response</th>
<th>Sex</th>
<th>Age</th>
<th>SES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males compared to females</td>
<td>Older compared to younger</td>
<td>Upper compared to lower</td>
</tr>
<tr>
<td><strong>Does this happen All of the Time or None of the Time - difference in means (n providing a response)</strong></td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Does your doctor communicate with you clearly? (n = 394, df = 392)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Do doctors listen enough to your problem? (n = 396, df = 394)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Do specialists treat you with respect? (n = 366, df = 364)</td>
<td>-</td>
<td>-3.1 * More</td>
<td>-</td>
</tr>
<tr>
<td>Agreement or Disagreement with each statement – difference in means (N = 400, df = 398)</td>
<td>3.5 ** Less</td>
<td>-</td>
<td>-3.5 ** More</td>
</tr>
<tr>
<td>Patients who are able to understand should always have some say in decisions about their medical treatment.</td>
<td>-</td>
<td>-3.1 * More</td>
<td>-</td>
</tr>
<tr>
<td>The patient’s quality of life should be considered in deciding whether to use lifesaving treatment or technology.</td>
<td>-</td>
<td>-3.1 * More</td>
<td>-</td>
</tr>
<tr>
<td>As a society, we need to learn to be more accepting of death.</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>I know what health services are available in my area.</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>When a person is extremely ill, and unlikely to live much longer no matter what treatment they have, doctors should always go ahead with any treatment that is possible.</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

* p < .01  ** p < .001
Table F8  Comparisons - What is Valued about the Public Health Care System and Four Philosophical Approaches to the Public Health Care System

<table>
<thead>
<tr>
<th>Item / Response</th>
<th>Sex</th>
<th>Age</th>
<th>SES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males compared to females</td>
<td>Older compared to younger</td>
<td>Upper compared to lower</td>
</tr>
<tr>
<td>What value about public health care system (% mentioned)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It’s free / Medicare system (35%)</td>
<td>-</td>
<td>-</td>
<td>12.0 ** Less</td>
</tr>
<tr>
<td>It’s there when needed (21%)</td>
<td>-</td>
<td>12.0 ** More</td>
<td>6.1 * Less</td>
</tr>
<tr>
<td>Nothing / No response (16%)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Availability in Geelong (16%)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Available for everyone (12%)</td>
<td>6.1 * More</td>
<td>-</td>
<td>18.6 ** More</td>
</tr>
<tr>
<td>Forced-choice comparisons:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good quality service chosen as more important than getting the service for free (85%)</td>
<td></td>
<td></td>
<td>24.7 * Less</td>
</tr>
<tr>
<td>Getting the service quickly chosen as more important than getting the service for free (73%)</td>
<td></td>
<td></td>
<td>9.2 * Less</td>
</tr>
<tr>
<td>Getting good quality service chosen as more important than getting the service quickly (61%)</td>
<td>-</td>
<td>-</td>
<td>7.1 * Less</td>
</tr>
<tr>
<td>Four approaches to the public health care system presented.</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Being equally available to all selected as the most important (73%)</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

* p < .01  ** p < .001
Table F9  Comparisons - Reasons for Making Funding Alternative Decisions (1)

<table>
<thead>
<tr>
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<tbody>
<tr>
<td></td>
<td>Males compared to females</td>
<td>Older compared to younger</td>
<td>Upper compared to lower</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Chi-Square (1, N = 400)</td>
</tr>
</tbody>
</table>

Community based services OR Hospitals

Reasons given

- People need hospitals when illness is serious (29%)  -  -  8.8 * Less
- Hospitals need money now (25%)                       -  -  -
- Both are important (22%)                             -  -  8.4 * More
- Everything people need is in hospital (10%)          -  -  -

Curing illness OR Educating the public about health risks

Reasons given

- You have to cure / treat sick people (28%)           -  -  14.5 * Less
- Both are important (26%)                             -  -  8.9 * More
- Prevention is better than cure (24%)                 -  -  -
- If educate people, may avoid illness (15%)           -  -  -
- You can only do so much with education (12%)         -  -  -

* p < .01   ** p < .001
### Table F10  Comparisons - Reasons for Making Funding Alternative Decisions (2)

<table>
<thead>
<tr>
<th>Item / Response</th>
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</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males compared to females</td>
<td>Older compared to younger</td>
<td>Upper compared to lower</td>
</tr>
<tr>
<td><strong>Chi-Square (1, N = 400)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer research OR Intensive care units for people over 80?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reasons given:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer affects everyone (40%)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Over 80's have had a good innings (24%)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Cancer claims too many lives (17%)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Both are important (17%)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Previous / personal experience (12%)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Saving a mother who needs lots of care OR</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Saving a premature baby - needs lots of care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reasons given</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can’t choose between people (32%)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Mother may have other children to care for (26%)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Mother could have other children later (14%)</td>
<td>-</td>
<td>-</td>
<td>6.1 * Less</td>
</tr>
<tr>
<td>Mother is established member of family / community (11%)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Premature baby may have long term health problems (11%)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

* p < .01  ** p < .001
Table F11  Comparisons - Principles Underlying Health Care Decisions

<table>
<thead>
<tr>
<th>Item / Response</th>
<th>Sex</th>
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<th>SES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males compared to females</td>
<td>Older compared to younger</td>
<td>Upper compared to lower</td>
</tr>
<tr>
<td>Some people's behaviour contributes to their illness, for example people who</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>smoke or drink excessively.</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>They should be treated the same as other people in the health system. (75%)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Dealing with a situation where there is something that cannot be available to</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>everyone, for example an organ transplant where there is only one organ, everyone</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>should be treated equally regardless of age. (44%)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>When deciding which services to put money into, the most money should be put</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>into services which help the most people (59%)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Premature babies should be given intensive care regardless of their chances of</td>
<td>-</td>
<td>13.5 ** Less</td>
<td>-</td>
</tr>
<tr>
<td>survival (75%)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* * p < .01  ** p < .001
### Table F12  Comparisons - Who Should Make Health Care Decisions

<table>
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<tr>
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</thead>
<tbody>
<tr>
<td></td>
<td>Males compared to females</td>
<td>Older compared to younger</td>
<td>Upper compared to lower</td>
</tr>
<tr>
<td><strong>t-tests (N = 400, df = 398)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agreement or Disagreement with each statement – difference in means (N = 400)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surveys of the public’s opinions like this one should be used in planning health services.</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Some countries have a group of people from the community who contribute to making decisions about major issues facing the public health care system. Do you agree that that is a good idea?</td>
<td>-</td>
<td>2.9 ** Less</td>
<td>-3.8 ** More</td>
</tr>
<tr>
<td>If members of the community are involved in making decisions, only people who use the public health care system should represent the community.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If members of the community are involved in making decisions, only well educated, articulate people should represent the community.</td>
<td>-3.3 ** More</td>
<td>-3.4 ** More</td>
<td>-</td>
</tr>
<tr>
<td>Medical professionals should make all the decisions about the health care system.</td>
<td></td>
<td>-3.5 ** More</td>
<td>2.7 * Less</td>
</tr>
<tr>
<td>Politicians and administrators should make all the decisions about the health care system.</td>
<td></td>
<td></td>
<td>2.5 * Less</td>
</tr>
</tbody>
</table>

\* p < .01  \*\* p < .001
References


Australia on Disk (2000). Sydney: Dependable Database Pty Ltd.


The ethics of resource allocation. (1990). Proceedings of a symposium held at the University of Manchester during the 33rd annual scientific meeting of the Society for Social Medicine, Manchester.

