

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 Commission¹, 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 people² 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 community has of its public health care system*³. 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:

- (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 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 participant's 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 Charter⁴ 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.

On a more local level, the Victorian State Government's health policy⁵ 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 review⁶ 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"⁷ 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, 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 who was refused funding for a second bone marrow transplant by the Cambridge and Huntingdon Health Authority⁸, emphasises the dilemma of priority setting in the UK National Health Service. The second example⁹ involved another child, this time 7 years old, who was denied treatment for his bone marrow transplant from the State of Oregon, USA.

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.¹⁰

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 Rawls¹¹ 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 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 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.

¹ Health Insurance Commission, Internet Web Site 2001

² 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

³ Barwon Health Strategic Plan, 1998

⁴ WHO. The Ljubljana Charter on reforming health care. Geneva: World Health Organisation, 1996 as quoted by Coulter A. Seeking the views of citizens. *Health Expectations* 1999; 2 (4): 219-221

⁵ Australian Labor Party (Victorian Branch) *A Healthy Victoria* 1999 p 5.16

⁶ Department of Human Services (Victoria) *Restoring Elected Community Representation on Community Health Centre Boards* 2000

⁷ Coulter A. Seeking the views of citizens. *Health Expectations* 1999; 2 (4): p220

⁸ New B. on behalf of the Rationing Agenda Group. The rationing agenda in the NHS. *British Medical Journal*, 1996;312:1593-1601

⁹ Citizens Health Care Parliament, *Principles for Health Care Allocation*, 1988 Report as cited by Street A. and Richardson J. The value of health care: what can we learn from Oregon? *Australian Health Review* 1992; 2: 124-134

¹⁰ Beauchamp T.L. and Childress J.F. *Principles of Biomedical Ethics* Fourth Edition, Oxford University Press, New York, 1994 p327

¹¹ Rawls J. *A Theory of Justice*, Oxford University Press, 1973 p4