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THE ETHICAL PRINCIPLES WHICH GUIDE THE ALLOCATION OF HEALTHCARE RESOURCES TO RURAL CHILDREN

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Abstract

This thesis describes research into the way Australian government officials decide to allocate healthcare resources for children who live in rural and remote areas of the country. It is known that infant mortality and health outcomes are worse for these children than for urban children. Moreover, there is evidence that rural families are more likely to experience difficulties gaining access to healthcare for their children than urban families. Documents and guidelines published by federal and state health departments suggest that the allocation of healthcare resources should be guided by the principles of equity and of obtaining the greatest possible improvement of the health of the whole population for the money spent. Prima facie, these principles are mutually incompatible.

Aim

This investigation was designed to answer the following questions:

1. What healthcare resources are currently available for children in rural and remote areas in Australia?
2. How do the parents of children living in rural and remote areas of NSW experience the provision of healthcare resources for their children and the consequences for their child and family of that pattern of resource provision?
3. How are healthcare resources allocated to children living in rural and remote areas and what factors are taken into consideration in making this allocation?
4. What ethical framework underpins the allocation of healthcare resources for children now?
5. What ethical framework could guide healthcare resource allocation for children in a way that best fits the needs of rural children, of their families and of government health officials?

Methodology

To gain a picture of the healthcare resources available to rural children in NSW, the decision-making process which led to the current distribution of those resources and the experience of rural families in gaining access to those resources, I employed complementary qualitative and quantitative approaches. In early 2018, information on the geographic location of healthcare resources relevant to the needs of children in the Western New South Wales (NSW) Local Health District was obtained from the National Health Services Directory and compared with the location of child populations of various sizes in geographical units known

as State Suburbs. To compare family experiences in gaining healthcare for their children, raw data were obtained from the NSW Health Child Population Health Survey, and the experiences of rural families in their interactions with several kinds of healthcare resource were compared with those of urban families.

Elected and non-elected officials of the Australian Government Department of Health and Ageing and the NSW Ministry of Health were interviewed, and themes identified from the transcripts. From this analysis, descriptions of the aims and process of healthcare resource allocation decision-making emerged, including description of the constraints on decision-making and the role of ethical considerations. The analysis also revealed the views of decision-makers on the nature of the ethical principles which guide resource allocations.

Findings

Comparison of geographical locations of healthcare resources with those of child populations revealed that healthcare resources needed by rural children were lacking in many localities containing substantial child populations. This evidence partly explains the findings that rural families were more likely than urban families to experience difficulty in accessing healthcare for their children, especially due to lack of resources, long delays in waiting time for scarce resources or transport difficulties in accessing them.

Interviewed officials indicated that elected officials (health ministers) and members of the National and NSW Cabinets held the ultimate power to make allocation decisions, and that those decisions had budgetary and political constraints. Ethical principles appeared to play only a minor role in allocation of healthcare resources, and while equity was the principle most often mentioned, there was no agreement on whether equity of resource allocation, equity of access to resources or equity of health was the aim.

Discussion and Implications

The investigation canvassed a range of metaethical principles which could inform resource allocation decision-making. It concluded that equity (and especially vertical equity) in access to healthcare resources for equal need was the principle most likely to be acceptable in Australian society and to Australian resource allocation decision-makers. At the same time, it appeared to be the most likely to improve the health and wellbeing of rural children, both absolutely and in relation to that of urban children.

Despite the investigation's identification of the value of equity of healthcare access, there is a discrepancy between the published intentions of the Australian Government Department of Health and NSW Health to allocate healthcare resources according to this principle, and the minor role which ethical principles, including equity, play in actual decision-making. Further, there is lack of certainty among officials about the goal of achieving equity (that is, whether equity in resource allocation, equity in healthcare access or equity in health should be the aim).

The investigation suggests two principal reasons why the avowed aim of allocating resources to achieve equity was not, in fact, achieving equity of health or of healthcare access. One was the apparent uncertainty among officials about the aspect of health or healthcare in which equity was to be achieved. The other reason was deficiency in motivation to act on an acknowledged moral reason (to act to achieve equity). The data suggest that adoption of the

motivating principles of communitarianism or compassion would be more likely to supply the motivation to act to achieve equity than the assumption that the interests of the individual should underlie all ethical principles.

Declaration

This is to certify that:

1. This thesis comprises only my own original work towards the degree of Doctor of Philosophy
2. Due acknowledgement has been made in the text to all other material used.
3. The thesis is less than 100,000 words in length, exclusive of tables, maps, bibliographies and appendices.

Signed:

ROBERT DARIEN HENNING

Date:

Acknowledgements

This study developed from my interest in the provision of paediatric care to children in rural Victoria when I was administering the Victorian Paediatric Emergency Transport Service, based in the Paediatric Intensive Care Unit of the Royal Children's Hospital, Melbourne. I supervised a retrospective study of rural emergency retrievals, performed by Ms (now Dr) Leanne Kruizinga, a medical student from the Erasmus University of Rotterdam. Dr Kruizinga worked hard to collect, analyse and report retrieval data, and I am grateful to her for stimulating my own interest in the wider topic of delivery of healthcare to rural children. To pursue this investigation towards development of a hierarchical system of paediatric care for the State of Victoria, Australia, I was helped and encouraged by my first doctoral supervisors, Emeritus Professor David Dunt of the School of Population and Global Health of the University of Melbourne and Associate Professor Susan Donath of the Clinical Epidemiology and Biostatistics Unit and the Department of Paediatrics in the University of Melbourne. I am very grateful to both of them, particularly for their help in refining my research topic.

When the topic was modified to an investigation of the ethical grounds on which healthcare resources are allocated to rural children, I transferred the study to the Department of General Practice of the University of Melbourne and found my current supervisors: Associate Professor Victoria Palmer, Professor Meredith Temple-Smith and Dr Patty Chondros. All three of them were extremely helpful during the long progress of my part-time study, with endless encouragement, generosity with their time, very useful suggestions, and patience with my limited availability and slow progress. Not every PhD candidate has supervisors like these.

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Abbreviations

ABI	Acute Brain Injury
ABS	Australian Bureau of Statistics
ABF	Activity Based Funding
ACSC	Ambulatory Care Sensitive Condition
ACT	Australian Capital Territory
AHS	Area Health Service
AIHW	Australian Institute of Health and Welfare
ARIA+	Accessibility/Remoteness Index of Australia
ASGS	Australian Statistical Geography Standard
A4R	Accountability for Reasonableness
CBA	cost-benefit analysis
CEE	Centre for Epidemiology and Evidence of the NSW Ministry of Health
CEO	Chief Executive Officer
CI	confidence interval
COAG	Council of Australian Governments
CUA	Cost-utility analysis
DRG	Diagnosis-Related Group
ECI	early childhood intervention
ED	Emergency Department
GDP	Gross Domestic Product
GP	General (medical) Practitioner
HREC	Human Research Ethics Committee
IR	Inner Regional level of remoteness

LHD	Local Health District
MC	Major Cities level of remoteness
MCRI	Murdoch Children's Research Institute
NCOA	National Commission of Audit (established by the Australian Government)
NHS	National Health Service of the United Kingdom
NICE	National Institute for Health and Clinical Excellence, UK
NSW	New South Wales
NSWCPHS	NSW Child Population Health Survey
NSW Health	New South Wales Ministry of Health
OR	Odds Ratio
PBAC	Pharmaceutical Benefits Advisory Committee
PBMA	Program Budgeting and Margin Analysis
PBS	Pharmaceutical Benefits Scheme
QALY	quality-adjusted life year
RA	Resource Allocation
RAWP	Resource Allocation Working Party (of the UK Government, 1976)
RDF	Resource Distribution Formula
ROS	Rest of State (Outer Regional plus Remote plus Very Remote areas)
SA1	Statistical Local Area 1
SSC	State Suburb
UK	United Kingdom
UN	United Nations
US	United States
WHO	World Health Organization

Glossary

Agency	The capacity of an individual to take action
Appropriation bill	A law which authorises the disbursement of public funds
Capitation funding	A funding system in which a central funding agency distributes funds to subsidiary agencies (Local Health Districts, hospitals or individual practitioners) according to some prediction of the number of patients the subsidiary will treat and of the cost of treating each patient
Catecholamines	A group of related hormones including adrenaline and noradrenaline, which are produced in response to a variety of stresses, and which tend to increase the heart rate and blood pressure
Cost-utility analysis	An economic analysis in which the cost of a healthcare program or procedure is compared with the improvement in health or well-being which it produces
Epidemiology	The epidemiology of a disease or health state refers to the risk factors and causative factors which affect its incidence and distribution within a population
Federal Government	The government of the Commonwealth of Australia
Illawarra	Coastal region of NSW extending approximately 160 km south of Sydney
Inverse care law	The empirical observation that the most socio-economically disadvantaged geographic regions, which are those with the greatest healthcare needs, tend to be the least well served with healthcare resources (1, 2)
Medibank	A system of publicly funded universal health insurance introduced by an Australian government in 1975, but changed by a later Australian government in 1976 to a private form of health insurance. Publicly funded universal

	health insurance was re-introduced in Australia in 1984 as Medicare
Meta-ethical principle	A moral principle which purports to differentiate good from bad and a right action from a wrong action
Moral agency	The capacity to act according to some conception of right and wrong
Odds ratio	A means of comparing the likelihoods of occurrence of two events. If p is the probability of an event occurring, then the odds of it occurring is p÷(1-p). The odds ratio of the two events is the ratio of the odds of the two events.
Premier	The chief minister of an Australian state: an elected official
Royal Far West	A charitable organisation in NSW concerned with the health and welfare of rural children
SA2	A Geographical subdivision of Australia. The Australian Statistical Geography Standard (ASGS) of the Australian Bureau of Statistics divides all of Australia into 2310 SA2 areas without any gaps or overlap. Corresponds to a functional area from which people come to gain access to services. Roughly corresponds to a State Suburb. Population range 3,000 to 25,000. Each SA2 represents a social and economic community.
SA4	A geographical subdivision of Australia. The ASGS divides the Australian continent and its islands into subdivisions for the purpose of publishing regionally-based statistics. SA4 is the largest level of subdivision smaller than a state. One hundred and seven SA4s cover all of Australia without any gaps or overlap
Semi-structured interview	A form of interview in which the interviewer asks a list of questions which are designed to cover the topics of interest but are phrased so as to encourage the interviewee to freely discuss aspects of the topic without limiting the discussion

Standardised Mortality Rate	The number of deaths per 100,000 of the population in question, where the age and sex structure of the population is adjusted mathematically to be the same as that of a standard population. It is used to compare mortality rates of two populations of differing age and sex structures
State Suburb	Geographical area defined by the Australian Bureau of Statistics. Each State Suburb (SSC) consists of smaller contiguous areas defined within the Australian Statistical Geography Standard. An SSC corresponds approximately to a Gazetted Locality (a named region in Australia of which the boundaries are defined by the Committee for Geographical Names in Australasia). SSCs can vary in size from less than a square kilometre in cities or large towns, to many thousands of square kilometres in sparsely populated remote areas
Telemedicine	The delivery of healthcare, including diagnosis, treatment and follow-up, to patients remote from the clinician by means of telecommunication, usually audiovisual
Utility	Ability to satisfy a want. That want may be something which an individual values, or which contributes to the individual's perceived wellbeing. Marginal utility is the increment in perceived wellbeing produced by an initiative such as a healthcare procedure or program

Chapter 1: Introduction and background

Rural children have less favourable health outcomes on average than urban children and experience more difficulty in accessing healthcare, which is an important contributor to the improvement and maintenance of health. Australian state and federal health departments have a major role in determining what healthcare resources (such as hospitals, health centres, clinics and treatment programs) are available to people in rural areas. Australian government documents mention the need for equity (a person-regarding ethical concept: that is, one which values the wellbeing of individuals rather than the aggregate wellbeing of a population) in allocation of healthcare resources, but also mention the importance of obtaining the best value (in terms of the health of the whole population) for the money which governments spend on healthcare.

Cost-utility analysis (CUA) of government healthcare programs and of individual treatments is used to guide decisions about which programs and which treatments will be funded by governments. Overall utility is a population-regarding concept: that is, it refers to the sum of benefits gained by all members of the population. When the principle which guides the allocation of healthcare resources is to achieve the best aggregate health of the whole population, some individuals and groups in the population (e.g. rural people) can be left with less access to healthcare and with less favourable health outcomes than other groups (e.g. urban people).

Rural children appear to suffer from all of the healthcare access disadvantages suffered by other rural residents, but this issue is complicated, in that the decision to live remotely from optimal healthcare was not the child's decision, and the child's ability to access healthcare independently of adults is very limited. As well, the interests of other members of the family may compete with the interests of an individual child in accessing healthcare.

For these reasons, there appears to be a case for governments to give additional consideration to the interests of rural children when allocating scarce healthcare resources. The aim of this research was to examine the ethical frameworks which currently underpin healthcare resource allocation (RA) and to study their role in relation to RAs which affect the exceptionally dependent situation of the rural child.

1.1. The research objective

The objective of this research was to identify the ethical frameworks that should guide the provision of healthcare resources to children in rural and remote areas.

To approach this objective, the following research questions were addressed:

1. What healthcare resources are currently available for children in rural and remote areas in Australia?
2. How do parents experience the provision of healthcare resources for their children and the consequences for their child and family of that pattern of resource provision?
3. How are healthcare resources allocated to rural children, and what factors are considered?
4. What ethical framework underpins the allocation of healthcare resources for children now?
5. What ethical framework could guide healthcare resource allocation for rural children in a way that best fits their needs and those of their families and government health officials?

1.2. Background

The next five sections of this chapter discuss the nature and importance of health, the various determinants of health and the role and importance of healthcare. The main focus of this thesis is on rural children and their health and healthcare needs as moral agents. As sections 1.11 and 1,13 point out however, children are incomplete moral agents because of their dependence on others. This dependence makes them vulnerable to the actions (or lack of actions) of others, including those of government. Incomplete agency also means that discussion of the importance of health and of healthcare to agency applies increasingly to children as they progress through childhood and adolescence. Incomplete agency constrains, however, the ability of children to interact independently with the society and the ability of an investigator to include the voices of children in the investigation. For this reason, the next five sections discuss health and healthcare and their importance to moral agents. The child's development of moral agency and the importance of becoming a moral agent are discussed in section 8.6.

Section 1.8 presents the evidence that there is a problem with the health of rural children and that their health outcomes are less favourable than those of their urban counterparts. Section 1.9 discusses the concept of access to healthcare and its various dimensions, including accessibility, of which one factor is the remoteness of the child's dwelling from the population centre which accommodates the healthcare resource in question. Section 1.10 focuses on remoteness. As a first step in considering the problem of the healthcare disadvantage of rural children, we should consider the nature and importance of health.

1.3 What is health?

The World Health Organization's (WHO) definition of health, formulated in 1946 and contained in the current (2006) WHO Constitution, states that "Health is a state of complete physical, mental and

social wellbeing and not merely the absence of disease or infirmity" and that "The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, or economic or social condition" (3). The WHO's definition of health has been widely criticised as being unachievable in practice (4-9), although individuals whose state approximates that ideal could be seen as healthy.

Competing definitions of health exist. In 1985, Norman Daniels defined health (for the purpose of examining equity in healthcare) as "the absence of … deviations from the natural functional organization of a typical member of the species"(10). This definition, by emphasising the importance of the person's function, leads to Sen's portrayal of health as a necessary condition of capability and agency (11), but raises the questions of how much deviation is needed to be regarded as unhealthy, exactly what characteristics should be regarded as normal, and how variations between sexes, racial groups and generations should be treated.

Other, possibly more practically useful definitions, such as that of Huber et al. (2011), suggested that health should be defined as "the ability to adapt and self-manage" (5). However, in view of the relative dependence of children (the focus of the current research), it is not clear that this kind of very broad definition can adequately describe child health, nor is it helpful when one is examining the ethical principles which guide the allocation of healthcare resources. A 90-year old or an adolescent with Down syndrome, for example, may suffer from no illness but be unable to adapt or self-manage: they may require resources, but not necessarily healthcare resources. Although the concept of health remains nebulous and its definition imprecise, the health of an individual is important to her/him and to the community. The next section discusses the reasons for that importance.

1.4 Why health matters

Things (including objects, states of the world, qualities and actions) may be good in themselves (intrinsically good) or they may be good because they lead to, or are necessary for, another thing which is itself good; that is, they are instrumentally good (12). Some authors have claimed that health is intrinsically good (13, 14): Downie et al. (1996) argued that because health is a part of human flourishing (and not merely instrumental in the production of flourishing), it is incumbent on us as humans to value human health as a good in itself (13).

Duncan (15), however, presented an opposing argument that because significant numbers of people surveyed either do not value health above other goods, or feel that good health is of only minor importance or is unnecessary for a happy life (16), respect for the autonomy of those people

requires us to assume that they are “acting according to their own beliefs about health and its nature as a value,” and because for those people health is not a supreme good, it cannot be said to be a supreme good for all humanity. Duncan then argued that if all instrumental and subjective importance were stripped away from health, it could not be seen to have intrinsic value (15). Following Callicott (17), he argued that all reasons why a thing might have intrinsic value are ultimately subjective and therefore implausible as generalisable reasons. Whether health does or does not have intrinsic value, it is still agreed to have instrumental value in that it enables us to fulfil “the innumerable projects of life that we are all involved with” (15).

Norman Daniels, who defined health (as mentioned above) as “absence of deviations from the natural functional organization of a typical member of the species,” argued that preservation of natural functional organisation is morally important because it is needed to preserve the normal range of opportunity for a person in that society. That is, to preserve “the array of life plans reasonable persons in it are likely to construct for themselves” (10). Health, therefore, has moral and ethical dimensions which are important to consider, especially in relation to RA, and which remain under-explored.

This view of health as an instrumental good was taken up by Sudhir Anand, who pointed out that health allows a person to function as an agent: that is, “to pursue the various goals and projects in life that she has reason to value.” Anand argued that this view of health is not a utilitarian one, being based on its ability to confer agency rather than on its ability to lead to a good overall outcome (18). Pursuing a similar line of argument, Amartya Sen considered health to be “a critically significant constituent of human capabilities which we have reason to value” (11). That is, health is necessary, though not sufficient, for individuals to have the opportunity to act and to be, in ways which they desire, for their life to go well. Since health appears to be important then, we should consider the factors which contribute to an individual’s health.

1.5 Contributors to health

Factors other than healthcare (discussed in section 1.6 below) make very important contributions to the state of health of an individual. These include genetic and congenital factors (including chromosomal abnormalities and environmental factors which affect foetal development), as well as environmental causes of ill-health such as trauma, infection or exposure to toxins, nutritional causes such as starvation and dietary indiscretion, and the advent of illnesses of occult cause such as neoplasia (cancer) or autoimmune disease. Some environmental factors are particularly important influences on the health trajectory of all members of the community; these are the social determinants of health (19, 20).

Social determinants of health

The social determinants of health are those social, environmental, cultural and economic circumstances of an individual or a population group which influence the states of health and the health outcomes of the individual or group (21) through combinations of psychological, behavioural and physiological mechanisms. For example, social isolation and work stress appear to increase blood pressure (and thereby increase the risk of heart attack and stroke) by increasing the endogenous production of catecholamines, and increase susceptibility to a variety of infections by impairing cell-mediated immunity (22).

The various social determinants interact with each other, and disadvantages in these determinants tend to cluster in individuals, families and geographical areas (19). Disadvantage in childhood, including inadequate emotional support and mental stimulation and slow physical growth, increases the likelihood of adult illness, behavioural problems in childhood and adolescence, poor educational achievement and disadvantage in obtaining work (19). The “social gradient in health” (23) refers to the low life expectancy and high likelihood of lifetime ill-health experienced by those in lower socioeconomic groups compared with those in higher socioeconomic groups. Unemployment, under-employment, stressful work and poor working conditions all contribute to the social gradient in health and to the lower life expectancy found in lower socioeconomic groups (19).

The availability of and proximity to transport affects ability to attain satisfactory education, to obtain satisfying, remunerative and less stressful work, and access to social supports, leisure activities and exercise. Living close to busy transport routes such as arterial roads or busy rail junctions, however, can entail stressful levels of noise, exposure to air pollution and increased risk of accidental trauma. Offsetting these drawbacks are the benefits of walking or cycling to school, work or shopping, which include reducing the risks of obesity, diabetes and heart disease (24).

Excessive use of harmful substances such as tobacco, alcohol or drugs, on the part of an individual or a close family member, especially a parent, reduces the income available to be spent on healthy housing, food, clothing, transport and the activities that contribute to a healthy life. It can also cause injury through toxicity to cells and organs, carcinogenicity and (in the case of drugs and alcohol) by increasing vulnerability to trauma(25, 26).

Health can be impaired because of inadequate intake of total calories or of specific essential nutrients, leading to impaired growth(26). Excessive intake of salt may cause hypertension leading to heart disease and stroke(27), and excessive caloric intake increases the risk of obesity, diabetes and hypertension with their burden of reduced life expectancy(26).

All of these social determinants of health can be influenced and their ill effects mitigated at least to some extent by the actions of governments. Increased availability of better-quality public housing and better public transport can improve access to work, schooling, healthcare and leisure activities, and can reduce social isolation (19). Sustained education campaigns about appropriate nutrition, exercise, antenatal care and substance abuse, together with policies on price and availability of foodstuffs, at least offer the possibility of reduction in harm and improvement in long-term health and life expectancy (19, 28).

Although it appears that these non-healthcare factors play a major role in determining health outcomes and the state of health of individuals and of populations, healthcare plays a valuable role in maintaining and improving health. The aim of the research described in this thesis was to examine the ethical assumptions which underlie allocation of healthcare resources. States of health produced by non-healthcare factors, such as social determinants, and genetic, developmental and environmental factors, are a form of substrate or a given, on which healthcare and healthcare resources are required to act. The following section examines the role of healthcare in determining health outcomes.

1.6 What is healthcare?

Healthcare is "the organized provision of medical care to individuals or a community" (29).

Does healthcare contribute to improvement in health?

Until the mid-1970s, it was widely believed that improvements in healthcare were the major determinant of improvement in the health of individuals and populations (30). In 1976, Thomas McKeown published the results of a retrospective study of cause-specific mortality in England and Wales from 1848 to 1971. He found that 74% of the reduction in overall mortality over this period was in mortality due to infectious diseases, and that this reduction preceded the introduction of medical advances such as vaccination and antibiotics. Rather, he concluded, these decreases in mortality followed improvements in population nutrition, with a lesser contribution from improved population and individual hygiene (including sewerage systems and safe water supply) since the 18th century (31).

Since the publication of McKeown's work in the 1970s, it has become widely accepted in Australia (21, 32, 33) and elsewhere (30, 34-37) that social determinants of health have a major role in determining the health of individuals and populations. In contrast to the pre-1970s era, when healthcare advances were frequent and rapid and healthcare itself was assumed to be the major contributor to improvements in health, the contribution of curative healthcare to the health of

individuals and populations is now regarded in the public health and sociological literature as a relatively minor though expensive one (30, 34). Moreover, it distracts the attention of governments and planners from larger contributors to population ill-health and consumes a large and increasing proportion of gross domestic product (GDP; see below). The reasons for this disproportionate attention that is given to curative healthcare are many, but include persistence of historical attitudes, the political power of medical providers and the healthcare establishment, and the relative ease with which "downstream" curative care can be instituted compared with the difficulty of dealing with major "upstream" determinants of health, such as poverty, social isolation, inadequate housing and substance abuse (30, 32).

McKeown's conclusions, however, have been widely criticised, and other authors have retrospectively reviewed mortality data in comparable countries (37-39). In 1996, Mackenbach reported that in the Netherlands the reduction in overall mortality between 1875 and 1970 was very similar to that found by McKeown for the same period, and that the contribution of reduction of infectious disease mortality was of similar magnitude (39). Mackenbach also found, however, that the rate of decline of all infectious disease mortality increased by 150% (from 4% per year to 10% per year) after the introduction of antibiotics (39). This is an especially impressive acceleration, given that many infectious diseases which can cause death are not susceptible to antibiotics (e.g. measles, influenza A and B, neonatal herpes simplex and neonatal varicella).

Mackenbach estimated from the available epidemiological data that in the Netherlands, the contribution of medical care to the decline in total mortality between 1875 and 1970 was between 4.7% and 18.5% (39). Furthermore, in the modern (post-World War II) era, it is the efficacy of contemporary medical care that is important, effective treatment of the fatal diseases of today only having become available in the last 50 years (39-41). Bunker estimated that about half of the 7.5 years increase in United States (US) life expectancy from 1950 to 2000 was attributable to medical care (38). Much of the more recent (post-1950, i.e. in the antibiotic era) reduction in US mortality is due to reduction in deaths due to pneumonia, influenza, cerebrovascular diseases including stroke, heart disease, diabetes and end-stage renal failure, with a smaller contribution from reduction in cancer mortality (38). These are treatment-responsive conditions.

Finally, there is evidence that healthcare affects health outcomes in Australian children. In Western Australian children with acute lymphoblastic leukaemia (the commonest childhood cancer) for example, event-free survival has increased from 15% to more than 80% in the last 40 years due to improved medical care (42). Survival of extremely low birthweight infants (i.e. birthweight 500 to 999gm) in Victoria increased from 25.6% in 1979–80 to 66.9% in 2005 due to improved care of

extremely premature infants, without a significant increase in the incidence of severe neurological disability in the survivors (43). Because health is important to the individual, and healthcare appears to contribute to the improvement of health outcomes, we should consider whether healthcare and its distribution in a population are morally important.

1.7 Does healthcare have special moral significance?

Another way of expressing this question is: should the distribution of healthcare among individuals or groups be treated separately from the distribution of other goods such as wealth or education because there is something special about healthcare? (44)

In 1985, Norman Daniels argued that healthcare should be distributed more equally than other social goods because a healthcare response to a need (e.g. in the form of an illness) is required to preserve the individual's range of opportunity to fulfil her/his life plan (10). Moreover, this response is often needed in a situation of vulnerability and therefore has moral significance. In Daniels' formulation, a life plan is the way an individual wishes her/his life to proceed: he employed Rawls' narrow definition of a life plan as "the rational plan for a person (which) determines his good" and is "that plan … which would be chosen … with full deliberative rationality, that is, with full awareness of the relevant facts and after a careful consideration of the consequences" (45). Although Rawls appears to expect a life plan to include the acquisition of employment, social position and power, this conception of what makes a life go well has been criticised (46) because the conditions for formulating such a plan are rarely met, and in any case, "the happiness that life affords us is less often the good we have reason to pursue than the good that befalls us unexpectedly" (46).

Segall (2007) argued that Daniels' basis for regarding healthcare as special on these grounds was unsound. First, because it could not justify allocation of healthcare to the elderly, who could be said to have fulfilled their life plans, and second, because healthcare appears to be less important in influencing the health of individuals, and hence their opportunities to fulfil their life plans, than are the social determinants of health (44). Segall's argument on the first point hinges quite narrowly on Daniels' reliance on Rawls' principle of fair equality of opportunity "for jobs and careers" (44, 45) to support his (Daniels') argument. A more general definition of a life plan which encompasses the preservation of capabilities, freedom from pain and distress and the ability to enjoy the society in which one lives might be less susceptible to the first of Segall's objections, while still providing a plausible reason for regarding healthcare as special.

Although the social determinants of health may be more important than healthcare in determining the state of health of individuals and populations, they are *antecedent* causes. Once an individual

has become ill (as many people in any society do, at one or more times in their lives), healthcare becomes much more important and may often be the main factor which determines their survival. If the term "healthcare" includes health education and preventive measures such as vaccination, it also assumes a larger *antecedent* role in determining health. Indeed, this suggests that healthcare, thus defined, contributes to the common good of society.

A difference in health outcome of an individual illness such as epilepsy or road trauma between two groups of individuals (e.g. urban children and rural children) may be due to differences in the epidemiology of the illness (including the incidence of new cases and the prevalence, severity and clinical characteristics of the illness) or due to differences in the response of members of each group to the illness due to the social factors described in section 1.6 above. Differences in the nature, quality and accessibility of healthcare available to the two groups may also contribute significantly to differences in health outcomes. Therefore, in the present study, it is important to examine the evidence that differences in the availability of healthcare do in fact contribute to any differences in health outcome between urban and rural children. First, what is the evidence that rural children in Australia have worse health outcomes than urban children?

1.8 What is the evidence about the health outcomes of rural and urban children?

Although the overall health of Australian children is improving (indicated by falling perinatal and under-5 mortality rates), mortality rates of children in rural and remote areas of the country remain higher than those of urban children (47). Rural children are more likely than their urban counterparts to require hospital admission for conditions such as bronchiolitis (48), injury from road accidents (49) and unintentional poisoning (50), and for dental care (51). Some congenital conditions, such as developmental dislocated hip, are more likely to be diagnosed late in rural children than in urban children, sometimes with deleterious effects on long-term outcomes (52, 53).

As the next section will show, health outcomes experienced by rural children are worse than those experienced by children in metropolitan areas. Some of this difference in outcome is due to rural/urban differences in the epidemiology of some illnesses (e.g. the well-recognised higher incidence of blunt trauma among rural children (54)), but some differences in outcome may be influenced by the difficulty which rural children often experience in gaining access to the particular healthcare service which they need.

Rural-urban differences in childhood illness

Rural children are a heterogeneous group (55). They differ in socio-economic status, ethnicity, and degree of rurality; some children live on farms, while others live in rural towns or settlements. These differences in the child's circumstances may affect his/her risk of becoming ill, as well as his/her access to healthcare if he or she *does* become ill. The illnesses suffered by children in the country are broadly similar to those suffered by urban children, but some illnesses suffered by rural children differ in type, frequency, underlying factors and outcome from those that afflict urban children.

Reliable data on the *prevalence* of childhood illnesses and on the *incidence of new cases* in Australia are available for very few kinds of illness. This leads to reliance on indicators such as mortality and the frequency and duration of hospitalisation, for which data do exist for individual illnesses.

Mortality in rural children

All-cause mortality in children in developing countries tends to increase with remoteness from major centres of population, especially as poverty increases and access to vaccination, public health measures and electricity decline with increasing remoteness (56). In developed countries, the picture is more complex. For example, in countries such as Australia, the US and Canada, where distances are great and there are areas of marked rural poverty, child mortality is generally greater in rural than urban areas (57-59), whereas in European countries such as the United Kingdom (UK), where poverty and disadvantage are most marked in urban areas, child mortality is greater in cities than in rural areas (60). In South Australia over 2005–13, child deaths per 100,000 child population varied from 28.6 in major cities to 36.2 in inner regional areas, 37.8 in outer regional and 48.5 in remote or very remote areas (61) (See Appendix 1 for a description of Australian remoteness categories). In Australia as a whole in 1998–2000, the mortality rate of children aged 1–14 years increased with increasing remoteness (Table 1). In particular, deaths due to injuries and poisoning, and those due to respiratory and cardiovascular illness, were more common in rural children.

Infant mortality (death rate of children less than one year of age) in Australia also increases progressively with increasing remoteness (62) (see Table 2). Other industrialised countries in which healthcare resources are concentrated in urban areas report the same phenomenon. In the US in 1992, for example, the mortality rate of children of all races aged 1–14 years was at least 20% higher in rural children than among urban children (13). Mortality rates among Canadian children also increased progressively from urban to the most remote areas. See Table 3.

Not all disadvantage in health outcomes, however, is reflected in mortality. Residual disability, avoidable hospitalisation and prolonged hospital stay are all more likely when access to healthcare is

difficult. Although the amount of residual disability per illness episode is difficult to measure, length of hospital stay and hospitalisation rate per 1000 children in the area under consideration (e.g. children in remote areas versus children in major cities) can be compared using routinely collected data, as the next section illustrates.

TABLE 1 DEATHS PER 100,000 AUSTRALIAN CHILDREN AGED 1-14 YEARS, 1998–2000

Data from Al Yaman (2002) (57)

Cause of death	Metropolitan	Rural	Remote
Injury and poisoning	6.1	9.4	18.4
Neoplasms	3.6	2.8	2.0
Nervous system	1.8	1.7	2.7
Congenital malformations	1.3	2.0	2.7
Endocrine, metabolic and nutritional diseases	0.8	1.0	0.7
Infections and parasitic diseases	0.7	0.8	0.5
Respiratory system	0.7	0.7	2.4
Cardiovascular system	0.7	0.6	1.5
Other	1.2	1.3	2.0
Total deaths	16.7	20.2	32.8

TABLE 2 INFANT MORTALITY PER 1,000 LIVE BIRTHS, AUSTRALIA, 2018

Remoteness area	Infant deaths
Major cities	2.9
Inner regional	3.5
Outer regional	4.3
Remote	4.4
Very remote	7.3

Data from ABS (2019) 3302.0 Deaths, Australia, 2018 (62)

TABLE 3 AGE-STANDARDISED ALL-CAUSE MORTALITY PER 100,000 CANADIAN CHILDREN AGED 0–19 YEARS, 1986–96

Age group	Urban	Rural	Most remote
0–4 years	156.7	177.7	257.0
5–19 years	29.2	48.1	76.8

Data from Canadian Institute for Health Information (2006) How Healthy are Rural Canadians?(63)

Morbidity in rural children

Although reliable statistics on the incidence of non-fatal acute illness are difficult to obtain, it is clear from routinely collected data on hospital and emergency department (ED) admissions and length of hospital stay that rural children have worse health outcomes than urban children, especially in traumatic injury, infections, cancer, respiratory illness and youth suicide. These rural–urban differences are described in detail in Appendix 2. Although some of the differences in health outcome appear to reflect differences in the incidence of illness (e.g. trauma), rural disadvantage in access to primary healthcare appears to be responsible for worse outcomes (in terms of hospital admission rates and length of hospital stay) in common childhood illnesses such as infections, respiratory illnesses and cancer (see Appendix 2). Two possible indicators of such differences in healthcare are amenable mortality and the rate of hospital admissions due to ambulatory care-sensitive conditions (ACSCs).

Amenable mortality

The expression “amenable mortality” refers to the mortality rate per head of the population group being discussed (urban children or rural children) that is due to illnesses that are agreed to be amenable to treatment and for which “it is reasonable to expect death to be averted even after the condition has developed” (64). Defined in this way, amenable mortality is a subset of avoidable mortality (65) (deaths which can in theory be avoided by preventive measures – such as better road maintenance or better nutrition – or by treatment).

In 2014, a group based in Warwick, UK published a review of the causes of child death in high-income countries, including Australia and New Zealand, from the work of Child Death Review Committees in those countries (66, 67). The authors divided the causes of child deaths into four groups: biological and psychological factors (including genetics, ethnic origin and behaviour); physical environment; social environment and factors in service delivery (which included access to healthcare and the nature and quality of available healthcare). There is a considerable literature on

overall (mainly adult) amenable mortality in Australia and elsewhere (64, 68-73), including the effects of living remotely on amenable mortality (64, 70, 74). Little of that published literature in Australia, however, examines amenable mortality in children and the effects of remote dwelling (75), and none examines the effects of remote dwelling on amenable mortality in individual illnesses. Similarly, no literature examines the improvements in healthcare provision, staffing or organisation which would be needed to ameliorate rural–urban differences in amenable mortality.

In the UK, several studies have investigated childhood deaths and factors which may have contributed to them (67, 73, 76). In 2008, the UK Confidential Enquiry into Maternal and Child Health reported its findings about 957 child deaths and factors which may have contributed to them, including inadequacies in primary care, in-hospital care and in coordination between ambulatory, hospital and specialist services. It also identified shortcomings in palliative care services in some areas and made recommendations for ameliorating the deficiencies it found (76). No such Australia-wide studies have been published (66), although the findings of Child Death Review Committees of individual states are published annually (77-80). These committees examine individual deaths and suggest ways in which they might have been prevented.

Publications in 2007 from the Public Health Information Development Unit of Torrens University (81) reported the total amenable mortality rate per 100,000 population of young people aged 0–24 years in Australian urban and rural Divisions of General Practice[a]. Amalgamating child mortality with that of the 15–24-year age group however, distorts the picture of urban–rural difference in amenable mortality because the amenable causes of death in that group are very different from those of children aged 0–14 years (82). Apart from these reports, no published investigation or reporting of amenable mortality by individual illness in Australian children, or of rural–urban differences in it, is known.

Wolfe et al., in a 2014 report entitled *Why Children Die: Death in Infants, Children and Young People in the UK,* examined healthcare-amenable mortality in children as a criterion by which the effectiveness of one health system can be compared with that of another. They pointed out that estimates of the proportion of health gain that can be attributed to healthcare vary widely (83), and mostly refer to the health of the adult population. Furthermore, they noted, child deaths are few, so that the number of deaths from any single diagnostic category is even smaller, making any interpretation of amenability almost impossible, especially as the degree to which an individual

[a] Divisions of General Practice were regionally-based voluntary associations of general (medical) practitioners, created by the Australian Government in 1992 to improve the quality, coordination and accessibility of primary healthcare services. They were superseded in 2011 by Medicare Locals and in 2015 by Primary Health Networks.

child's illness was amenable to treatment varies widely between cases (73). The effect of small numbers on interpretability is particularly relevant to rural areas, in which the child population is smaller still. Even combining mortality statistics from several years makes interpretation in children little more reliable (73). A further limitation on amenable mortality as an indicator of healthcare adequacy is the fact that many deaths have an underlying cause (e.g. cerebral palsy or chronic lung disease of prematurity) and a proximate cause (e.g. viral pneumonia or pneumonia from aspiration of gastric contents). In these circumstances, selection of the underlying or the proximate as the cause of the child's death becomes problematic, and the degree to which death might have been prevented by healthcare difficult to judge reliably.

Another, more promising indicator of the effect of healthcare on health outcomes is the rate of hospital admissions for ACSCs.

Ambulatory care-sensitive conditions

Ambulatory care-sensitive conditions are illnesses or diagnoses for which effective care, delivered early in the illness (usually by a primary carer) is thought to be able to reduce the likelihood that hospital admission will be required. This is achieved by preventing the ACSC altogether (e.g. in the case of vaccine-preventable illnesses), preventing recurrences of an episodic illness such as epilepsy, or preventing complications of a chronic illness such as childhood diabetes mellitus (84).

Ambulatory care-sensitive conditions in children

Lists of ACSCs relevant to children have been proposed (85-88). They include bacterial pneumonia; gastroenteritis; dental conditions; asthma, immunisation-preventable conditions and epilepsy/convulsions (88); iron-deficiency anaemia; congenital syphilis and pulmonary tuberculosis (86). The Victorian Health Information Surveillance System has identified 14 such conditions that appear to be proxy markers of the adequacy of access to ambulatory care in Victorian children (89): dental conditions; asthma; ear, nose and throat infections; convulsions and epilepsy; pyelonephritis; cellulitis; acute complications of diabetes mellitus; influenza and pneumonia; dehydration and gastroenteritis; chronic obstructive pulmonary disease); hypertension; vaccine-preventable infections; iron deficiency anaemia; and gangrene. For some of these diagnoses, such as the acute complications of diabetes mellitus, there appear to be significantly more admissions per 1,000 rural children than is the case for urban children. For other diagnoses, such as epilepsy/convulsions, the rate of admission of rural children is approximately equal to that of their urban counterparts (89).

As Ansari has pointed out, most studies of the validity of ACSCs have examined the use of frequency of hospital admissions for collections of *several* diagnoses to assess the adequacy of access to primary healthcare (85). The evidence that admissions for *individual* diagnoses are reliable indicators

of access for patients with that diagnosis is scanty. For example, in the case of serious acute complications of diabetes mellitus in childhood, Thompson et al. (2001) found that in single-parent families, the number of missed clinic appointments predicted high glycated haemoglobin levels (90), which in turn have been shown to predict an increased likelihood of hospital admission for severe acute complications of diabetes (ketoacidosis or severe hypoglycaemia) (91). From these two sets of results, it appears that inadequate ambulatory care (indicated by the number of missed clinic appointments) is associated with an increased risk that the child will need hospital admission for the acute complications of diabetes.

Rural–urban differences in hospital admissions in childhood ACSCS in Australia

Table 4 shows that among Victorian children with diabetes in 2014–15, the standardised rate of hospital admissions per 1000 children was greater in children living in rural areas than in children living in metropolitan areas. This implies that primary care for rural children with diabetes in Victoria was poorer than that available to their urban counterparts.

TABLE 4 COMPLICATIONS OF DIABETES IN VICTORIAN CHILDREN, 2014–15. STANDARDISED RATE OF HOSPITAL ADMISSIONS PER 1,000 PERSONS

Age group		Metropolitan	Rural
0-4 years	Complications of diabetes	0.22	0.28
	All ACSCs	22.73	25.69
5-9 years	Complications of diabetes	0.57	0.74
	All ACSCs	17.63	21.44
10-14 years	Complications of diabetes	0.98	1.22
	All ACSCs	8.17	9.01

Data from Victorian Health Information Surveillance System (92)

This section shows that the rate of childhood mortality, and the morbidity from some illnesses, is worse for children in rural and regional Australia than for urban children, and that the rates of hospital admission for some ACSCs are greater for rural than for urban children. These results indicate that rural families in Australia experience greater difficulty than urban families in obtaining access to healthcare when it is needed. The next sections discuss the concept of access to healthcare and the effect of living remotely from centres of population on access to healthcare.

1.9 What is access to healthcare?

The most widely accepted description of healthcare access is that of Penchansky and Thomas, who in 1981 described access as "a general concept that summarizes a set of more specific dimensions describing the fit between the patient and the healthcare system. The specific dimensions are availability, accessibility, accommodation, affordability and acceptability" (93).

Availability refers to adequacy of supply of healthcare personnel and facilities; accessibility is the geographical relationship between service and client, taking into account the distance the client would have to travel to gain access to the healthcare and the time this would take. These in turn depend on the location of the patient (usual domicile); the location of the health service; the geography of the road network; the state of the roads (including the frequency of weather-dependent road closures); availability of public transport; possession and availability of a car; ability of the patient or family member to drive, and travel time (85). Of these, possession of a car and ability to drive are characteristics of individual families and so are not under the control of healthcare planners, though when many families in a community are unable to drive or have poor access to private transport, this may be taken into account in planning health services for that community. Accommodation is the relationship between the client's needs and the way the service is organised; affordability includes the client's perception as well as the actual relationship between cost and ability to pay; acceptability refers to the relationship between the client's attitudes about personal and practice characteristics of providers and the actual characteristics of the providers and the service (93). The last two are particularly relevant in the case of Indigenous clients.

Parents of children living in rural Australia are more likely than urban parents to report difficulty in obtaining healthcare when needed (94). Qualitative studies of the healthcare experiences of rural parents have described the process of obtaining healthcare for a sick child and the disruptive effect of that process on family life and employment (95). In other countries, families living in regions distant from major population centres have reported problems with access of their children to healthcare resources. In sparsely settled countries such as the US, Canada and Australia, as well as more densely settled countries such as the UK, children living in rural and remote areas have less access to healthcare than urban children (96-101). Some North American studies have found that poorer healthcare access for rural children than for urban children was associated with worse outcomes from illnesses such as appendicitis and major trauma (100, 102-104).

A US survey of families of children with special healthcare needs (defined as children with a condition lasting at least 12 months, that involves limitation in their ability to do things that other children could do, need for prescription drugs, specialised therapies or extra medical, mental health

or education services or need for treatment for an emotional, behavioural or developmental problem) found that rural children were less likely to be seen by a paediatrician and were more likely to have unmet healthcare needs because of transportation difficulties or because necessary healthcare resources were not available in their area (105). Furthermore, Mayer et al. (2005) pointed out that reports of the frequency of unmet needs of rural children are likely to be underestimates: for example, in a US study, when rural families did not perceive the need for an important health service, as commonly occurred, they did not report it as an unmet need (106, 107).

Differences between Australia and other countries in cultural attitudes to healthcare, in distribution of socioeconomic and educational disadvantage and in transport conditions that affect healthcare access, mean that international findings have limited relevance to Australia. Because living remotely from population centres large enough to require and support healthcare resources such as hospitals, clinics and general practitioners has long been recognised in Australia as an important factor which limits the ability of the rural population to gain access to these resources when needed, the ABS has, for several decades, maintained and periodically upgraded a system of remoteness classification for all land and sea areas under the jurisdiction of the Australian Government. The classification currently in use is described in Appendix 1. The next section discusses the concept of remoteness and its significance for access to healthcare.

1.10 What is remoteness?

Remote is an adjective meaning situated away from the main centres of population or society; distant; free of or cut off from the features of civilization or industrialisation; secluded; unspoilt (29). The Oxford English Dictionary's definition of remote includes two main elements: physical distance and geographical relationship to centres of population. Both elements are important determinants of the ease (or difficulty) with which a patient or family can reach a healthcare service.

Indicators of remoteness

For the purpose of health service planning, members of the population are grouped (e.g. by income, ethnicity or remoteness of domicile) rather than treated as individuals. In the case of remoteness of domicile, it is the remoteness from relevant health services of a geographical area in which people live that is the variable of interest. Appendix 1 contains a brief description of the Australian Bureau of Statistics (ABS) Remoteness Classification of Australia, and Appendix 3 describes the geographical distribution of the child population of Australia between areas of various degrees of remoteness from population centres.

When considering the effect of remoteness of domicile on the accessibility of health services for people living in a geographical area, one of several surrogates for the remoteness of that area can be used: first, distance (especially road distance) between the area and a population centre which is populous enough to retain the relevant health service; second, the population density within the area; third, some combination of distance and population density, or fourth, travel time between the area and a population centre.

Population size of an area

The larger the population of an area, the more likely it is to contain healthcare resources. For example, a town of 5,000 people is more likely to be able to attract and retain at least one general practitioner (GP) than a town of 1,000 people. A town of 50,000 people is more likely to contain a secondary referral centre (known in Australia as a base hospital) than a town of 10,000 people. A city of 1 million people is more likely to contain a tertiary referral hospital (e.g. a university teaching hospital) containing specialist services such as a paediatric emergency and intensive care departments, and staffed by sub-specialist paediatricians, paediatric surgeons and paediatric emergency physicians, than a town of 50,000 people.

Population density

Density (e.g. the number of inhabitants per square kilometre) is widely used as a surrogate for rurality, and hence for access disadvantage, to classify populated areas for the purposes of allocation of funds for healthcare and to assess health needs and healthcare outcomes(108). Appendix 1 describes how the ABS categorises areas of Australia by remoteness from population centres of various sizes. The ABS and the Australian Institute of Health and Welfare (AIHW) use these remoteness categories to compare the health of rural people, and the availability to them of healthcare resources, with those in more populous areas. Appendix 2 describes the distribution of the child population of Australia by degree of remoteness.

The effect of remoteness of domicile on access to healthcare

The road distance from a family's house to the healthcare resource which a child requires (whether this is a nurse-led clinic, a GP, an ED, a general paediatrician or a paediatric sub-specialty service) is one determinant of the ease or difficulty of gaining access to that service. Other determinants, in the case of road travel, are the availability of a family car and driver when they are needed, the nature of the roads (which may vary with the season) and the terrain to be traversed. People living very remotely (e.g. in the north-west of NSW, the Kimberley in Western Australia or in western Queensland) may have road access to a nurse-led clinic or to a GP, but require air transport to specialist facilities if these are needed. In that case, access to those specialist facilities is limited by

the availability of a suitable air ambulance and by the flight time, which can be many hours. While some primary care resources, such as GPs, nurse-led clinics, walk-in clinics and Aboriginal health centres are located in smaller towns as shown in Chapter 5, more specialised facilities such as inpatient hospitals and paediatric services are usually found only in larger centres.

The following section discusses factors which affect the ability of children (as opposed to adults) to gain access to healthcare. This is relevant to the question of whether special consideration should be given to their needs and interests when decisions are made about the allocation of healthcare resources.

1.11 What factors limit a child's access to healthcare?

Apart from obvious external issues such as dependence on adults for transport and financial resources, the child's access to healthcare resources is limited by several factors related to the child's stage of development. Experience of health resources and how to contact them, and how to make use of them for one's health needs, only accumulates in late childhood and early adolescence. Children who have had little exposure to healthcare structures and clinicians under the tutelage of their parents will eventually learn how to make independent use of these resources (by direct or proxy – e.g. via communication media – experience), but may gain that skill later than children who have extensive early exposure (109, 110).

The executive skills, such as attentional capacity, planning and problem-solving skills and working memory, needed for an individual to interact independently with healthcare organisations develop at different times, but in most children are not well developed until early adolescence (111, 112). This means that children in middle or late childhood should not be expected to assess their own healthcare needs or to plan and execute a consultation with a healthcare organisation. The maturation of executive functions and competence depend on brain maturation, especially of the pre-frontal cerebral cortex, with establishment and remodelling of inter-neuronal networks in that region (113). This brain maturation and its accompanying functional maturation occur at different rates. Maturation of executive function in an individual child, like physical growth, does not occur at a single steady rate from beginning to end, but rather in an irregular series of spurts and pauses (114).

The age at which each phase of this maturation process occurs and the rate at which maturation occurs are influenced by several factors. As well as influences like gender, nutritional state and drug and alcohol consumption (113), these factors include the culture of the community and especially that of peer groups. An adolescent will expect her or himself to be able to perform a given task, such

as arranging and attending a GP appointment without parental assistance, if the culture among peer group members is that this should be so. This culture varies from one community and era to another (114). Competences that are expected in a 13-year-old in a rural area may not be the same as those expected in a suburban peer group of 13-year-olds in a major city. Over the last 100 years in Western countries, the concept of "adolescence" (defined by the WHO as the ages from 10 to 19 years (115)) has become engrained in public consciousness, with (it is claimed), infantilisation of young people (WHO definition: ages 10 to 24 years (115)), reduced expectations of competence in the teenage years, and consequent delay in achievement of some components of social competence (114).

The values, experiences and cultural beliefs of the parents, as well as the parents' parenting style (e.g. authoritarian versus authoritative (114, 116)) strongly influence the rate of development of executive functions during childhood and adolescence. A child who is given the opportunity to make decisions, and so gain experience in decision-making, will achieve competence more rapidly than one who is told what to do by an authoritarian parent (116, 117). The child's environment (e.g. the availability and nature of healthcare services locally, the distances to them and the availability of transport) may limit the child or adolescent's opportunities to exercise and develop competence in accessing such services. Each of these influences may operate to a greater or lesser extent in children in a rural area, such that there is a spectrum of distribution of achievement of social competence in rural children, and at any given age that spectrum may be quite wide. This means that abilities and competences which are evident in some children or adolescents of a given age will not be present in others, and any pattern of distribution of healthcare services for that group of children will have to take account of the fact that a significant group of children or adolescents of that age has not achieved those competences to access healthcare services independently.

Given this wide spectrum of capability of rural children to access healthcare independently, and the centralised nature of healthcare services for children in rural Australia, it is important to examine the experiences of rural children and adolescents and of their families in gaining access to healthcare for them. The next section will examine the evidence in the published literature and the grey literature on this topic.

1.12 Experience of rural children and their families in gaining access to healthcare

Rural families' experiences of their children's interactions with the health system are likely to vary with the geography of the country and the organisation, funding and dispersion of healthcare

resources. Family experiences in countries such as the Netherlands, where distances are short and health insurance universal, are likely to be different from those in the US Midwest, where distances to towns with health resources can be great, and health insurance, especially for the rural poor, can be barely adequate. This means that for a study of Australian children, the most relevant reports are those from Australia, though these are fairly sparse, and those which provide detailed reports of families' experiences tend to focus on particular groups of children or particular healthcare needs. Most surveys of patient experience suffer from limitations such as respondents being self-selected and those wishing to express a complaint being more motivated to respond than those who wish to praise. The range of questions and the range of answers to each question are restricted, so the picture of the situation which that survey reveals is necessarily partial (118).

The Report on Child Health, based on the NSW Ministry of Health's annual Population Health Survey (101), describes the results of a random telephone survey of families with children in each of the eight NSW Area Health Service (AHS) areas, of which four were urban and four rural. The results of an analysis of the patient experience part of that survey for the years 2011–14 is presented in Chapter 5, and the methods of that analysis are described in sections 4.5-4.8. Although NSW Health continues to conduct these health surveys, questions on patient experience of healthcare have not been included in the questionnaire since 2014-15. It is also noteworthy that while the ABS conducts regular patient experience surveys, only persons aged 15 years and over are surveyed (119), and there appear to be no plans to conduct national surveys of children's experience of healthcare. Hence, identification of how children experience the healthcare system is lacking in Australia.

A 2007 study of the effect of health policy and its implementation on children's access to healthcare described the experiences of 128 families who participated in 16 focus groups. Participants in the two small central NSW towns that were studied were not well informed about the healthcare services that existed, where the services were located or how to access them. They were aware that healthcare services relevant to their children were poor, but reported that they were unlikely to lobby for improvement in their child's access to those services, even when they were needed (120). A later report by the same researchers, focussing on socio-economically disadvantaged rural adults and their children, found that these families relied on local services and especially on local GPs for the healthcare of their children, many of whom had complex physical, emotional and mental health problems, even when more specialised and possibly more effective services were available in regional towns or in cities. These participants reported little knowledge or choice of, or control over, types of healthcare or health outcomes. The authors noted that conventional health education and public health measures seemed to have had little impact on the health literacy of these families and hence on their children's ability to profit by health policies intended to benefit them (121). Allan et

al. noted also that the population of rural poor in Australia was increasing because of the availability of low-cost housing in small towns (121).

The experiences of children and adolescents in rural Australia suffering from specific conditions such as cancer, head injury and mental illness have been described in several articles. Monterosso et al. (2009)(122) reported on the support and palliative care needs of children dying of cancer in Western Australia, Queensland, NSW and Victoria (122). Thirty per cent of this sample of families lived in rural areas. The authors pointed out that palliative care for children had to cater for needs that were different from those supplied by adult palliative care services, because of psychological, developmental and life experience differences, parental involvement and the preference for home care, as well as the need to provide care and support for siblings. This meant that without special training in palliative care for children and close backup from children's cancer centres, palliative care services for adults were not able to supply the needs of dying children.

Similarly, a study of acute brain injury (ABI) rehabilitation services in rural and remote NSW found that services overall were much more difficult to access than was the case in the city: skilled and experienced staff were difficult to recruit and to retain, and adult rehabilitation services did not cater for the special needs of children with ABI. Families of children with ABI in rural areas found that the costs of transportation, accommodation and time off work for parents were extremely burdensome, even in those areas where a rehabilitation service was available. This meant that rehabilitation services in the first 12 months after ABI, which can make a major difference to long-term functional outcome, were inadequate or foregone (123).

Characteristics of adolescents such as cognitive immaturity and their stage of psychological, emotional and social development, together with their self-consciousness and lack of experience in dealing with the health system, impede their access to the healthcare that they need (124). Booth et al. found that while many adolescents aged 12–14 years were happy to rely on their parents to take them to health services, many of the adolescents who participated in their 81 focus groups had little knowledge of available services, and factors such as lack of anonymity and lack of a female GP (especially a young female GP) in rural areas meant that participants were more likely consult a friend, a parent, a sibling or someone they knew and trusted, rather than attempting to access a health service (124). This implies that the cultural appropriateness of healthcare services is not well matched to the healthcare needs of adolescents, and that their inadequate access to healthcare due to this maladjustment of services is particularly acute in rural areas.

The experiences of disadvantaged (rural/remote, homeless, Indigenous or refugee) adolescents in accessing healthcare were described in a report from the University of Sydney and the University of

Technology, Sydney (125). Interviewees emphasised the appropriateness of a service as a factor which limited their access to it. Apart from the financial cost of transport and its availability, considerations such as the availability of a female GP, or the critical attitudes of GPs or support staff, together with embarrassment, shame and lack of anonymity in small towns, limited the willingness of vulnerable rural youth to access services (including mental health services) that they needed (125).

A narrative review of mental health services for adolescents in rural Australia described why many do not seek help for mental problems even when they recognise that they need help (126). Cost of consultations and unwillingness to use services paid for by their parents were significant barriers to access, in addition to the factors already mentioned. Boyd et al. commented that some characteristics of rural communities, such as "the politics of inclusion and exclusion," social visibility and stoic rural attitudes also tend to exacerbate this relative inaccessibility of healthcare for rural youth (126).

Specialised allied health services for children in rural areas appear to be affected by problems of scarcity, central location, long waiting lists and high transport costs, in a manner similar to that which besets conventional medical services. Parents of children living in rural and remote areas of Australia who were in need of speech pathology services were surveyed by O'Callaghan et al. (2005) via a mail-out questionnaire (127). Respondents reported that in many areas there was no speech pathology service locally, or if there was a service there was very limited choice and long waiting lists, leading to delays in access or to access being foregone. Parents and their GPs were often unaware of speech pathology services. In many cases, travel to the nearest speech pathology service was expensive, requiring access to private or public transport (127). This picture reflects that seen with other allied health services and with medical, dental and mental health services, described above. The effects of this difficulty of access of rural children to the healthcare services that they need are described in section 1.9.

The next section canvasses the proposition that the attributes of childhood are such that governments which allocate healthcare resources across a large population, urban and rural, adult and child, should consider the healthcare needs of rural children differently from the way the healthcare needs of adults are considered, and that the healthcare resources and organisations required to cater for their healthcare needs should be modified accordingly.

1.13 Should rural children be treated differently from adults?

Rural children have a claim to be treated by government decision-makers in a way different from the way in which competent adults are treated with respect to access to healthcare. This is because children are dependent on others, for choice of domicile and so for their proximity to health resources, and for the means (e.g. transport; accompaniment by a parent; decision-making about whether and when to consult a clinician) by which they can take advantage of existing healthcare resources. The good of one child in a family may not be a dominant (or even a major) consideration in the decision of a family to live in a rural or remote area (128-130) rather than close to a city or large town where paediatric healthcare resources are more readily available.

The severity of this problem in its effects on children and their families is increased by the fact that childhood illness is different from adult illness, and specialised expertise for dealing with it is much less widely available than that for adult illness (131, 132). This makes the allocation of scarce healthcare resources among a heterogeneously distributed population of children a more severe problem than is the case for adults.

In what ways, morally relevant to the allocation of healthcare resources, are children different from adults?

Decisions which affect a child's circumstances are very often made by others. Ross (1998) gave the example of Amy, a 9-year-old with cerebral palsy. If Amy can get better rehabilitation in a larger town or city, her parents may decide to leave their residence in the country and move to a larger town. Alternatively, they may decide to stay where they are and that Amy will have to settle for less than ideal healthcare (133). In making this sort of decision, parents have to balance the benefit or loss of benefit to one child against the benefit or loss of benefit to other children in the family, to the parents themselves and to the family as a whole. In Ross' example, moving to the city may cause loss of educational and emotional benefit to Amy's sisters, who must leave their school and social network, or to the family as a whole, if moving means the breadwinner(s) lose jobs and income and the family becomes destitute (133).

Parents, or potential parents, often make decisions about where to live based on factors unconnected with the interests of their present or future children. Economic factors such as the availability of work and transport and the level of remuneration for either or both parents may be the principal determinants of the choice of the family's domicile, and the health and other interests of the child may be secondary, if they are considered at all (134, 135). Once the decision to settle in

a place has been made, there are considerable cost and social disincentives to move, even when a family member's (for example, a child's) health status changes (133, 134).

Brighouse and Swift (2006) pointed out that even liberal philosophers, who believe that the right of persons to control their own lives should not be overridden except when that right conflicts with the rights of others, do not assign the same rights to children, over whose lives adults (usually parents) exercise control. Brighouse and Swift argued that it is permissible (within limits) for parents to pursue interests which may conflict with those of their children and that it is wrong for the state to prevent this (136). Such interests may include living close to work or close to grandparents or on a family property for reasons of work, income, family loyalty or fondness for a way of life.

Studies in Eastern and Western Europe, Australia and Latin America found that contact with family and friends, as well as living in rural areas, are independently beneficial for life satisfaction and subjective wellbeing (137). If these results are applied to the parents of children, then it appears that the interests of rural-dwelling parents (and secondarily of their families) may be advanced by their remaining in the country. Given this evidence that remaining in a rural area, which may be remote from medical facilities, can advance the interests of parents (and possibly of healthy siblings and of the family as a whole), how should the interests of a sick or possibly-sick-in-the-future child be weighed against these competing interests?

Whose interests compete with those of the sick or possibly-sick-in-the-future child?

Parents

Like any sentient beings, parents have interests. Some of these, such as an interest in remaining in preferred employment or living in a preferred location or engaging in education or leisure activities, may conflict with the interests of a child in receiving optimal healthcare. In the view of authors such as Aristotle (138) and Hobbes (139), the relationship between parent and child is one of ownership or domination, meaning that the interests of the parents have precedence over those of the child. If it were to be widely accepted that the parent–child relationship is one of possession and that the interests of parents had priority over those of the child, then there would be an unequivocal argument for a more extensive caring and supervisory role of the state in the provision and management of healthcare for the child.

More recent writers, however, offer different accounts of the nature of the family, with more emphasis on the needs and interests of the child. Houlgate, describing a principle of optimal communal benefit, discussed the family in the sense of a group of at least two people, at least one of

whom is a child, and at least one of whom is an adult who provides for the basic needs of that child. He suggested that although the justification for the existence of the family is partly based on its utility for the happiness of parents and children and for the effective raising of children, the actions of parents towards children and towards each other should be guided by the needs of children and their rights over their parents, possessed by virtue of their membership of the family (140). This rather stark, rights-based account deals only with the "basic goods" of the child (defined by Rawls as "those things that any rational man [sic] wants, whatever else he [sic] wants" (45)). It makes no mention of other possible interests of the child, such as quality education or preventive, risk-reducing measures such as preventive dentistry or vaccination. Nor does it provide guidance in balancing the interests of one child against those of her or his siblings or of the parents.

Even more unevenly balanced in favour of the needs and interests of the child (against those of the parent) is Jeffrey Blustein's account of the priority of parental duties. Blustein proposed that parents have duties of status, based on their position as parents, to provide the basic goods of the child, as well as taking into account the child's "wants and desires" in actions which affect the child. These duties have absolute priority over parents' rights, which can only be acted upon when duties towards the child have been fulfilled (141). This view of parental duties takes little account of the secondary benefit to the child which accrues when the parents are happy, with their needs and wishes satisfied and the needs of all members of the family fulfilled as far as is possible. Furthermore, it makes no mention of balancing the interests of one child against those of siblings.

LF Ross attempted to steer a middle course between those of Blustein and Houlgate. She proposed a guiding framework of constrained parental autonomy, operating within the intimate family, in which parents have flexibility in the way in which they provide the basic goods of each child, based on respect for persons rather than on the principle of acting in the "best interests" of the child (133). Given that "best interests" are difficult to identify, and as mentioned already, perceptions of best interests may differ between parent, child and impartial observer, Ross' proposed system appears more workable than best interests-based models. However, while Ross' proposal provides flexibility for the parent, it does not give very exact guidance on how parents should act.

Schoeman's description of ethical relations between parents on children is based on intimacy, which, he suggested, is a good in itself (142). Schoeman argued that the intimacy which determined relationships within a family meant that parents should have a claim against society to make decisions on behalf of their children. Apart from the obligation to provide the basic goods of the child, however, basing the moral relationship between parent and child on intimacy does not provide a guide for the actions of parents towards the child or the child's siblings. Indeed, the notion

of intimacy, formulated by Schoeman as blurring the moral boundaries between parent and child as individuals, tends to make it more difficult rather than less for a parent to discern the best course of action vis-á-vis a child. It provides no guidance to adjudication of the competing claims of a sick child and his or her siblings, or those of a sick child and the family unit itself. Schoeman's picture of moral relationships within a family, based on intimacy, specifically excludes a role for provision of care for the child by the state, except in circumstances of dereliction of caring duty by the parents. Schoeman admitted that "we are assuming that minimal conditions for adequate upbringing will be met" (143). This minimal provision of goods to the child seems to fall somewhat short of what might be considered necessary to preserve "the array of life plans reasonable persons … are likely to construct for themselves" (10), or to lead to the level of overall health which could permit the child to function as an agent and "to pursue the various goals and projects in life that she has reason to value" (144). Because of these inadequacies, it is difficult to find a role for Schoeman's view of parent–child relationships in guiding the state in the provision of resources, including healthcare resources to maintain the health and wellbeing of the child.

Siblings

Children (including siblings of an individual sick child) have needs and interests which may include security and need for a one-to-one relationship with at least one parent, predictability of daily events, and security of relationships and the environment. All children need and thrive on praise, especially from a parent. For development they need surroundings which provide new experiences and opportunities for safe experimentation and play (145). Satisfaction of these needs of the child's sibling(s) requires parental time and resources, which means that when one child has healthcare needs that another does not, parental resources might be stretched.

Siblings of children with severe or chronic illness have reported loss of family activities, loss of security and predictability in their own lives, loss of their own status within the family and of attention from their parents, and loss of the opportunity to engage in their own usual activities during episodes when their brothers or sisters were ill (146). Redirection of time and other resources towards the ill child may lead to (albeit unintended) quite severe neglect of the non-ill siblings (147), and parental efforts to prevent or compensate for this may act to the detriment of the ill child.

The family

Ross (1988) and Buchanan and Brock (1989) denied that the family per se has interests which are independent of those of its members (133, 148). This view is characteristic of the Anglophone tradition (149) of individual rights, but the communitarian tradition of Western Europe, especially of France and Germany, holds that the family has interests and rights other than those of its individual

members, and that those rights may conflict with those of its individual members (150), including, in this case, the sick or possibly-sick-in-the-future child. These interests of the family per se may include staying together as a family, remaining in a location (e.g. in a remote rural area) where one or more of the parents has gainful employment, and engaging in work, social or community activities which involve several members of the family, even if satisfying these interests reduces the time and resources available to supply the individual child's healthcare needs.

1.14 Summary

This chapter discussed the nature and importance of health and of healthcare and showed that rural children suffer a significant disadvantage in health and in access to healthcare compared with urban children. It also showed that children, including rural children, are less capable than adults of accessing healthcare for themselves, and that as well as being dependent on adults for access to healthcare, the interests of an individual child must compete with the interests of others within the family for the parent(s)' time and the attention needed to gain access to healthcare for that child. The chapter discussed the distribution of healthcare resources which are needed by rural children in Western NSW. The next chapter will discuss the way in which Australian health departments decide to allocate healthcare resources which may be needed by those rural children.

1.15 Structure of the thesis

Chapter 2 discusses rationing of healthcare and outlines the nature and the dimensions of rationing and why governments feel a need to ration resources. In Section 2.4, the various methods which *can* be used by government departments, in Australia and elsewhere, to allocate healthcare resources according to some system of priorities are described. The methods used *in practice* by governments in Australia and elsewhere to determine an order of priority to competing claims for limited healthcare resources are described in Chapter 3.

Chapter 4 describes the methods used in this investigation. These include establishing the location of child-relevant healthcare services in Western NSW, analysis of survey data on the healthcare experiences of rural families and interviews with rural parents and with government resource-allocation decision-makers. Chapter 5 describes the location of health resources relevant to children in relation to child populations of various sizes in rural NSW. It then sets out the results of analysis of survey data on the experience of rural families in accessing healthcare for their children. Chapter 6 describes the findings of interviews with officials of the Australian and NSW governments who have responsibility for deciding on the allocation of healthcare resources.

Chapter 7 canvasses a range of ethical principles which *could* guide such resource-allocation decisions and Chapter 8 discusses, in the light of the data described in Chapters 5 and 6, which of these principles might be most suitable to guide these decisions. It also discusses the relationship between espousing a principle and acting upon that principle. Chapter 9 summarises the findings and conclusions of the thesis.

Chapter 2: The allocation of healthcare resources

The preceding chapter outlined the problem of poorer healthcare outcomes for children in rural and remote areas of Australia and discussed the importance of health and the role of healthcare in maintaining health. This chapter will discuss the allocation of healthcare resources and examine the evidence about the role which ethical considerations play in the making of healthcare allocation decisions. If unlimited funds, facilities and personnel were available to devote to the healthcare of a population, then there would be no need to decide where to allocate resources: the healthcare needs of every member of the population could be met. In fact, however, every country in the world must ration healthcare resources, because the funds available for healthcare are inevitably limited.

2.1 What is healthcare rationing?

The term "rationing" refers to the process of allocation of healthcare resources when their availability is limited (151). Healthcare rationing means that some individuals who want and could obtain benefit from a healthcare resource will have access to it, while others who want and could receive benefit from a healthcare resource will be denied it (151, 152). Some writers suggest that rationing is a separate process from the setting of priorities for healthcare programs, in that "priority setting" refers to the process of determining budgets and their distribution, while "rationing" refers to the allocation of healthcare resources to individual patients within healthcare programs (153), while others regard this distinction as artificial, because decisions about RA between programs inevitably affects service or program delivery to individual patients (154). This thesis uses "rationing" to refer to the process by which governments or government departments allocate healthcare resources from the overall department budget to healthcare programs.

Governments have the responsibility for providing services in many areas, of which some, such as water supply, education and road maintenance, have more effect on health than others such as defence. Indeed, as described above, they may have more effect on health than the provision of healthcare services. There are several levels at which governments allocate resources in a way that affects the health of individuals:

- allocation of funds to resources which affect health within a global government budget;
- allocation of funds to healthcare resources within the total budget for resources which affect health;
- allocation of funds to individual services (e.g. ambulance service; acute hospitals; mental health services) within the total healthcare budget; and

- allocation of funds and services which benefit the health of particular groups of people (e.g. diabetics, women, pregnant women, children, Indigenous people, people living in remote areas (155)).

All of these allocations are referred to as macro-allocation (156). Allocation of services to individual patients (157) by clinicians or hospital administrators is referred to as micro-allocation (156). The allocation of healthcare resources to rural children, which is the concern of this thesis, is macro-allocation. Rationing of healthcare resources may be explicit, as in the classic example of the US state of Oregon (158), or it may be implicit (156). In 1990, the Oregon Health Services Commission produced a list of healthcare services in a priority order based on their cost-effectiveness. While Medicaid coverage was to be extended to 100% of poor people in Oregon, they would receive only those services which lay above a certain level of cost-effectiveness in this priority list. This was explicit rationing of total healthcare resources (the total Medicaid healthcare budget in Oregon). After the public and doctors criticised this list and its implications, the Oregon Health Services Commission released a revised priority list based only on effectiveness, regardless of cost. Patients would still receive those services that had been found to be effective, regardless of cost. The element of expenditure-based rationing had been removed (158).

In the Australian Pharmaceutical Benefits Scheme (PBS), the cost of some drugs is subsidised by the Australian Government. One criterion used by the Pharmaceutical Benefits Advisory Committee (PBAC) to decide whether to admit a drug to the scheme is "where there is no listed alternative (drug), PBAC considers the clinical place, overall effectiveness, cost and cost-effectiveness of the proposed medicine compared with standard medical care" (159). In other words, access to subsidised medicines will be explicitly rationed by subsidising only those that are judged to be cost-effective. This measure was introduced in 1993 in response to the rapid increase in cost of subsidising drugs (160).

Implicit rationing, as defined by Mechanic in 1997:

> … refers to discretionary decisions made by managers, professionals, and other health personnel functioning within a fixed budgetary allowance. A variety of rationing strategies can be used to control costs implicitly such as queuing, reducing the intensity of services, substituting less expensive for more costly services and deciding whether services are necessary. (161)

The rationing processes of some government health departments – including those of Australian states, which allocate limited funds according to the criteria of Accountability for Reasonableness (see section 2.4 below) – rely on fairness of process, which is a form of implicit rationing (162, 163).

2.2 Why governments ration healthcare

All governments are obliged to provide a range of services to the population for which they are responsible. The financial resources available to every government are limited. Therefore, every government must allocate those resources among the various services (such as healthcare, education, social services, defence and policing, building and maintaining infrastructure) for which it is responsible, according to some system of priorities.

Spending on health was the second largest expenditure item in the Australian Commonwealth Government budget for 2013–14 (19% of expenditure and 9.1% of GDP) (164, 165) and was the largest expenditure item in the combined budgets of all Australian states in that year (164). Australian Government health spending increased by 76% in real terms between 2002–03 and 2013–14 (164) and is predicted to require another 2% of GDP in Commonwealth budgets between 2013 and 2023 (164). Health expenditure (by federal and state governments) per head of population increased by 3.7% per year in real terms between 2000–01 and 2010–11 (166). Similar increases in health spending have occurred in other high-income countries (see Table 5). For example, US health expenditure is predicted to increase by 2% of GDP between 2010 and 2020 (167).

While health expenditure increases in real terms, the revenue collected by Australian Commonwealth and state governments is predicted to fall by 0.5 to 2.0% of GDP over the decade between 2013 and 2023 due to declining terms of trade, including falling minerals prices (164). This means increasing pressure on Commonwealth and state budgets unless the predicted increase in health expenditure is restrained. Restraint on health expenditure means that the money available for expenditure on healthcare will decline. When total healthcare expenditure is restricted, the total availability of healthcare resources which require expenditure will be restricted too.

TABLE 5 HEALTH EXPENDITURE OF HIGH-INCOME COUNTRIES AS % OF GDP, 2000, 2010–14 AND 2017

	2000	2010–14	2017
Austria	10.0	11.4	10.4
Australia	**8.1**	**9.1**	**9.2**
Canada	8.8	10.9	10.6
Denmark	8.7	11.2	10.1
France	10.1	11.7	11.3
Germany	10.4	11.3	11.3
Ireland	6.1	8.1	7.2
Israel	7.4	7.5	7.4
Italy	7.9	9.2	8.8
Japan	7.6	10.1	10.9
New Zealand	7.6	10.3	9.2
Spain	7.2	9.6	8.9
Switzerland	9.9	11.3	12.4
United Kingdom	7.0	9.4	9.6
United States	13.6	17.9	17.1

Data from The World Bank (2014) (165) and The World Bank (2020)(168)

Increased expectations of government-provided healthcare

Over the last hundred years at least, the standard of healthcare available to Australians has steadily increased, and in parallel with that increase, major indicators of population health, such as life expectancy at birth (Table 7) and under-5 mortality rate (Table 8) have improved.

TABLE 6 LIFE EXPECTANCY (YEARS) AT BIRTH IN AUSTRALIA

	1901–10	**2015-2017**
Males	55.2	80.5
Females	58.8	84.6

Data from AIHW 2019(169)

TABLE 7 DEATHS PER 100,000 AUSTRALIAN CHILDREN AGED 0–4 YEARS

	1910	**2017**
Males	2432	82
Females	2011	71
Persons	2225	77

Data from AIHW GRIM books (2019) All-cause mortality (170)

With that improvement in population health and increases in the availability of more and more advanced technology in the form of drugs, medical equipment and techniques for diagnosis and treatment, have come expectations. First, that those advances will continue and their benefits will be available to each individual when required, and second, that the government will provide them (171).

2.3 Dimensions of healthcare rationing

Putoto and Pegoraro described six dimensions of rationing; one or more of these may affect the satisfaction of the healthcare needs of a population group (172).

- selection of patients according to the expected amount of benefit or duration of treatment;
- denial of treatment to some populations (e.g. over an age or body mass index threshold, or smokers or users of illicit drugs). This may include under-funding services to some populations, such as rural populations, or closure of rural health facilities;
- deflection of patients to some other treating service or jurisdiction;
- deterring patients from accessing care by imposing administrative burdens such as paperwork and unhelpful staff, or locating healthcare resources at an inconvenient distance from the patient;
- delaying treatment, for example by allowing waiting lists to lengthen, which discourages patients from seeking healthcare; and

- dilution of care by providing services at a lower standard (e.g. by less-qualified staff) or a lower frequency (e.g. of clinic opening times).

2.4 How is healthcare rationed?

In this thesis, this question is interpreted as referring to the allocation of healthcare resources between geographical areas, between health facilities or programs, or between groups of patients when the total of these resources that is available is limited.

The question can be regarded in at least two different ways: first, what is the *process* by which healthcare allocation decisions are made, and second, what are the *reasons why* individual decisions are made? These two aspects are discussed separately below. Chapter 3 includes a review of the available evidence on the ways in which healthcare resources are rationed in practice in Australia. Resourcing priorities may be assigned to a list of competing claims using a variety of methods (173), outlined below.

Historical allocation

With this method, resources are allocated according to past practice and the existing geographical locations of facilities and healthcare providers. Maynard and Ludbrook portrayed the process as "what you got last year, plus an allowance for growth, plus an allowance for scandals" (174).

This often-used method can be applied rapidly and is less subject to political pressure than other methods, but offers little opportunity for innovation or for maximising health benefit, because allocation of resources to new, higher priority services can only occur if overall funding is increased (175). Geographical inequality in services is perpetuated, and indeed tends to increase under this system (176, 177), and those hospitals or health services which are more skilled at arguing their case for a larger budget (usually large city teaching hospitals and regional base hospitals) will continue to receive shares of total available funds out of proportion to the needs of the populations they serve (174, 177).

Decisions on the allocation of budgets to regional health authorities and to services such as public hospitals were strongly influenced by historical allocations in many countries, at least until the mid-1990s. In Australia, state governments allocated funds to health services (and in particular, hospitals) principally on historical grounds in order to "maintain the financial position of each hospital in real terms in the face of rising prices and costs" (178), at least until Victoria introduced diagnosis-related group (DRG)-based funding (an output-based funding method aimed at increasing the efficiency of hospitals) in 1993 (179). The same historically based pattern of RA can be seen in the fixed share of

total healthcare services that Australian governments allocated to public health between 1963–64 and 1995-96 (180). As Peacock and Segal pointed out, health services:

> that have historically high levels of utilization are rewarded with increased levels of funding in the future. Some of these patterns of high use reflect historical decisions about the location of health services that were largely unrelated to the healthcare needs of the population. (181)

In the UK, before the reorganisation of the National Health Service (NHS) in 1974, regional health boards bid for a share of national healthcare funding based on immediate past expenditure in their constituent facilities plus a component to "meet urgent developments and improvements" (174). In Canada, as late as 2012, a survey of senior executives of regional health authorities responsible for healthcare RA found that 24% of those surveyed believed that historical allocations were the primary driver of new allocation decisions by their organisation, and another 24% believed that political factors were the primary driver (182).

Capitation funding

Capitation funding of healthcare is a method used by a central body, such as the Australian Federal Government or a state government, to allocate funds among devolved entities such as local area health authorities or general practices, according to a pre-determined formula. The devolved entity is then expected to provide the full range of services for which it is contracted, to all of the members of the population for which it is responsible (183).

Those countries or jurisdictions which employ capitation funding for healthcare generally claim that it improves cost-effectiveness, equity and/or transparency of RA (184-186). Capitation funding has operated in at least 20 jurisdictions worldwide, including NSW, New Zealand, Alberta (Canada), Denmark, Belgium, England, Wales, Scotland, Finland, Italy, Germany, Israel, Japan, France and Spain (184, 185). The Australian experience with the use of capitation funding and its success or otherwise in achieving equity of healthcare resource allocation is discussed in sections 3.6 and 3.7.

Capitation funding is formula funding based on an expected level of activity (i.e. it is *prospective*) and its performance requirements are expressed as the number of individuals requiring healthcare. DRG funding (e.g. of hospitals in Australia), on the other hand, is formula funding based on reported activity (i.e. it is *retrospective*), the performance requirements of which are expressed as units of service (186). DRG funding is more vulnerable than capitation to excessive and inappropriate service provision and utilisation (183), while capitation funding may prove to be inadequate if actual need exceeds predicted need.

Capitation formulae have the general form $C = p*B + (a_1x_1 + a_2x_2 + a_3x_3 + ... a_nx_n)$, where C is the total payment for a population of p persons, B is a base payment per head, and x_1, x_2, x_3 … x_n are the sizes of subpopulations who require specific services 1, 2, 3 … n respectively, and a_1, a_2, a_3 … a_n are the cost weights that reflect the cost of provision of those services to individuals who require them. These specific services might include, for example, home GP visits for patients aged over 75 years, or developmental services for children with cerebral palsy.

Governments determine the aggregate amount available for distribution among the devolved bodies for providing healthcare (185). The various jurisdictions which use capitation have a variety of ways of calculating the amount disbursed to an individual devolved body (such as a Local Health District (LHD) in NSW (187) or a Clinical Commissioning Group in England (188)). In general, the factors (1,2,3 ... n in the example above) used to modify the payment formula are those which have been found to cause the healthcare utilisation rates of devolved body populations to deviate from that of the total population. These are known as needs factors (185).

Needs factors reflect those characteristics of the local population which affect its utilisation of healthcare funds per head. They may include demographic factors such as age and sex composition, ethnicity (e.g. Indigenous status in the NSW distribution formula), socio-economic status, geographical location (e.g. indices of population density in Alberta, Canada, or of remoteness in NSW) and disease status (184).

The needs factors applied in any capitation formula are those which have been found to explain the variation in healthcare spending patterns between devolved bodies in the recent past. One aim of capitation funding is to include only those factors which reflect healthcare needs and to exclude supply-dependent factors (e.g. GP visits per head of population are higher in areas with more GPs per square kilometre, and providers may increase their rate of service provision in order to maintain their income). Because needs factors and their weighting (by means of some form of multiple regression), are identified with reference to *past* service utilisation, it is difficult to exclude all supply-dependent factors (185).

As well as needs factors, capitation formulae often contain terms that allow for morbidity (measured, for example, by the hospital admission rate of a geographic population) and for unmet need (184). Unmet need may be general (when the aggregate amount to be allocated is insufficient to meet the needs of all patients within the populations served by the devolved bodies), or specific (when the healthcare needs of groups in the population such as rural children or patients with a particular illness are greater than those predicted in the allocation formula) (185). Allowance for specific unmet need may be made by increasing the capitation weightings for sub-populations

known to have poorer health outcomes (e.g. the Indigenous and homeless populations in NSW) or by increasing the weights for individual illnesses or individual geographic populations based on epidemiological data. England and Scotland employ the latter method (184).

Assessment of needs

Prospective methods of RA (such as capitation) depend on assessment of the healthcare needs of populations or sub-populations. The perception of unmet healthcare needs was a major driving force in the formation of the NHS in the UK in 1948 (189). In 1978, Knox described a revised process for allocating funds, personnel, buildings and programs to geographical regions, types of client and institutions in the NHS (which followed the 1974 reforms proposed by the Resource Allocation Working Party (RAWP)) in which the main considerations to be taken into account by the decision-maker were the needs which were to be met and the standard at which they were to be met (190). As described above, assessment of need is the basis of capitation funding in jurisdictions worldwide, including (in the recent past) NSW.

What are needs?

What does it mean to say that someone needs something? Needs statements have the general form A needs B in order to do C (191, 192). Wiggins distinguished the thing needed (the "satisfier"; B in the above formulation) from the process of needing (193). B may be a tennis racquet which A needs in order to play tennis, or it may be a life-saving medical treatment which A needs in order to survive. The moral force of possession of a need (that is, whether it does or doesn't impose an obligation on others to satisfy the need) depends on the importance with which the consequence (C in the above formulation) is regarded by the individual and by others in the society in which she or he lives.

If the need relationship is expressed in the form *A will achieve C if and only if A has access to B*, and the consequence C is one that is generally regarded as very important, then it is an absolute need and others have a duty to satisfy that need. If the proposition is true, then the converse – *if A does not have access to B, then A will not achieve C* – is also true.

What kinds of consequences can be agreed to be important? According to Wiggins, avoidance of serious harm is such a consequence: "a person needs X if and only if … he will be harmed if he goes without X" (189, 193). Doyal and Gough developed this theme by suggesting that serious harm is that which prevents "the pursuit of goals which are deemed of value by individuals." Further, they proposed that "To be seriously harmed is thus to be fundamentally disabled in the pursuit of one's vision of the good" (192).

Amartya Sen (194, 195) introduced the idea of harm as that which severely limits one's capabilities of achieving valuable "functionings … strongly valued by all," such as being adequately nourished, or achieving self-respect or being socially integrated. While individuals may value each of these functionings differently, the whole package of functionings is valued by all, and capability of achieving the package of functionings, according to Sen, is needed for the individual to have agency and the freedom to lead different kinds of life (195). Anything that significantly limits those capabilities constitutes a severe harm to that person.

Doyal and Gough suggested that the two most basic needs of an individual are survival and autonomy, and that autonomy is dependent on the individual's understanding of herself and of the society in which she lives, on her understanding, her "cognitive and emotional capacity" and on the opportunities (limited by her own physical capacity) available to her (192). Severe curtailment of any of these factors severely harms the individual, so in order to avoid serious harm to herself, she needs to avoid their impairment.

Needs as preferences

It is not always agreed that needs are categorical or that they have normative force. In orthodox economics, for example, since the time of Adam Smith, a need has been regarded as merely a preference (192, 196) which an individual may hold more or less strongly. For example, while one might regard the need to survive as a categorical need, many individuals assign lower priority to that need than to other preferences; for example, the soldier who sacrifices his own life to save his friend's. If this view of the nature of needs is accepted, the need as preference can be weighed against other preferences and can ultimately be assigned a monetary value. This, in turn, denies normative force to the concept of need.

Acceptance that what an individual needs is only that which she prefers implies that she has no needs of which she is unaware, that all individuals are sufficiently informed of the consequences of enactment or non-enactment of their preference, and that all individuals will always make rational choices. The obvious incorrectness of these assumptions casts doubt on the equation of need with preference (192).

Needs as wants

Needs are sometimes equated with wants, which hold much less moral force than an objective need for an important end (197). There are several reasons why needs differ from wants. First, each individual has needs of which he or she is unaware and which could not therefore be described as wants. For example, it is true that all humans *need* a small amount of manganese and selenium in their diet in order to avoid becoming severely ill (198), but few are aware of that need, so it cannot

be described as a *want*. Similarly, there are wants which are not needs: one might want a glass of expensive champagne but it could not truthfully be described as an objective need.

Second, the truth or falsity of needs statements such as *A will achieve C if and only if A has access to B* can be determined by empirical observation. These are statements about the external world and are verifiable by examining the world external to A, whereas want statements (e.g. *A wants B in order to achieve C*) are statements about the state of mind of A at the time (192, 199) and are verifiable only by questioning A.

The existence and nature of some needs (specifically, the nature of the satisfier) may vary from time to time and according to circumstances. For example, a parachutist needs a parachute in order to survive when she jumps from an aeroplane, but not at other times, and a child needs an antibiotic in order to survive severe bacterial septicaemia, but not at (most) other times. Other needs, however, are fundamental and do not vary with circumstances; these are those things that an individual always needs in order to avoid suffering serious harm (200).

Needs as interests

A less-commonly encountered view of the nature of needs is that someone's needs are the same as that person's interests, where interests are understood as a shared perception of what is good (189, 201). This view is derived from a particular reading (201) of Plato's Lysis (202), and although it does not appear to be widely shared, does support the notion of there being categorical needs which are independent of the desires of the individual.

What does having a categorical and important need imply?

The communitarian (see section 7.8) position on this question was formulated in the 18th century by Jean-Jacques Rousseau. According to Rousseau, living in a society necessarily implies some amount of mutual obligation, such that each member of the society has rights which are recognised and acted upon by all other members of the society (203). Doyal and Gough extended this proposition by suggesting that each individual within a society, by membership of that society, has a right to some minimum of satisfaction of their needs (192) and that that right imposes on all other members of the society a duty to satisfy those needs as far as they are able: "the capacity of individuals to recognize and exercise such reciprocity (of rights and duties among individuals) is what makes social life a possibility at all" (192).

Plant et al. pointed out that any moral system which demands that individuals act so as to achieve any goals or duties or fulfillment of purposes must require that those individuals survive and have autonomy. All moral systems, if they are to be coherent, must therefore accord to all individuals the

right to have those needs met which are essential for their survival and autonomy (192, 204). Sarah Clark Miller distinguished "constitutive" needs (those which are needed to establish or restore an individual's agency and which are essential to the individual and cannot be foregone) from "instrumental" needs (those which are needed for other ends than avoiding harm or maintaining agency). According to Miller, having a constitutive need obliges another person to act so as to satisfy that need (205). Similarly, support for a duty to satisfy another's categorical and important needs comes from Kant's limited duty of beneficence to others (206), based on shared status as sentient beings who are therefore obliged to acknowledge the same duties towards oneself.

Wiggins (1998) suggested that there are three important characteristics of a need which affect others' obligations to satisfy that need and affect its force when it is opposed to the claims of others (e.g. when resources are limited and a RA decision must be made about whose needs are more urgent). These are the *gravity* of the need (how much harm the individual will suffer if the need is not satisfied), the *urgency* with which the need must be satisfied in order to avoid harm, and how *entrenched* the need for X is (how likely the individual is to suffer harm even if all possible means of preventing harm are provided, other than supplying X) (207). Each of these attributes is graduated rather than binary: a need may be more urgent or less urgent than another need, and more entrenched or less than another (189). The overall magnitude of a person's need depends on some combination of gravity, urgency and entrenchment of the need (189, 207). The arguments given so far for a right to satisfaction of needs have addressed only the case of categorical needs to avoid serious harm. These arguments have been extended to cover lesser degrees of need (189, 192, 208).

Doyal and Gough introduced the concept of *intermediate needs*. These are things which humans require in order to survive and to act autonomously (192):

- food and clean water;
- protective housing;
- a non-hazardous work environment;
- a non-hazardous living environment;
- appropriate healthcare;
- security in childhood;
- significant primary relationships;
- physical security;
- economic security;
- appropriate education; and
- safe birth-control and childbearing. (192)

The nature of the satisfiers of each of these intermediate needs and the standard to which each is satisfied depends on the era and the culture in which the need is held. Thus, a form and standard of housing which would be held to be essential for survival and preservation of autonomy in 21st-century Western society may not have been considered to be essential in 18th-century African society or even in medieval European society, and the standard of education that is regarded as the minimum necessary in highly developed countries now would not be seen as appropriate for girls in patriarchal societies.

Based on the premise that humans act in order to achieve some end which, on some level, they value, Amartya Sen proposed that the most basic human need is freedom to achieve. He emphasised the distinction between the resources (e.g. innate resources, physical capabilities, intelligence or financial resources) available to the individual, and the freedom to use those resources to achieve the valued end (209). The functionings which an individual has reason to value might include gaining adequate nutrition, avoidance of premature illness, disability and death, participation in the life of the community and of the family, and retention of self-respect (209). Thus, the intermediate needs of the individual are all those things which are needed to achieve that basic, primary need for freedom to achieve (210). These might include things like access to transport, access to suitable employment, access to effective healthcare and locally available education.

Distribution of healthcare resources according to need

The present investigation concerns decision-making about the distribution of healthcare resources. The healthcare needs of groups of people in a population could be taken into account when decisions are made about the allocation of resources within that population. Culyer and Wagstaff examined definitions of need which relate to the distribution of healthcare resources (211).

Need as initial health

Some authors have treated need for healthcare as equivalent to ill-health (212), but Culyer and Wagstaff, arguing that the ill-health does not equate to need, claimed that a person with a severe illness for which there is no treatment could not be said to need healthcare (though they might be said to need comfort, pain relief, etc.) (211). This appears to be an artificial distinction, in that comfort measures are part of healthcare, even if no curative measures are available. Even if the concepts of initial health and need for healthcare are not co-extensive, having a significant illness for which some form of healthcare is available (however inadequate) is at least a precondition for having a need for healthcare. Culyer and Wagstaff pointed out, however, that one could need (preventive) healthcare without being ill (211).

Need as capacity to benefit

If a need is regarded as a necessary condition for achieving a goal which is recognised as important and valuable (such as an improvement in health or the prevention of ill-health), one could regard the need for healthcare as the capacity to benefit from that healthcare. This excludes ineffective healthcare and "unnecessarily costly" healthcare (211).

Need as expenditure that an individual ought to have

This definition of need takes account of the degree to which a need should be satisfied and allows the need of one individual to be compared with the need of another. The amount of the needed thing to which the individual is entitled may be determined by the degree to which the need ought to be satisfied (determined by community opinion), or it may be determined by the amount required to satisfy a need. Thus, person A may require more of a healthcare resource to move them into health state X than person B, so person A's healthcare needs are greater (211).

Need as expenditure required to exhaust capacity to benefit

This is the allocation of healthcare resources needed to provide the individual with the maximum possible improvement in health or to reduce the individual's capacity to benefit to zero (211).

Define core services and fund only those which can be so defined

This method of allocating services was adopted in the 1990s in New Zealand and the Netherlands and operates in one form or another in a variety of jurisdictions, including Queensland (213) and the Canadian province of Manitoba (214). Services are described as "core" if they satisfy criteria such as effectiveness, efficiency, fair use of public money and incorporation of community values (173, 215). Individuals are entitled to these services, while risk and outlay to the State are limited (176). In practice, however, variability in patients and their circumstances and in the cost of providing a given service made application of this system in its original form problematic and unworkable, given political pressures caused by unmet needs (176).

The core services model may also operate at within-hospital or within-area-health-service levels of RA. For example, the most effective treatment of some illnesses requires the use of high-cost medicines. When the budget of a hospital or an area health service is limited, officials of the hospital or health service must decide which services (including use of a high-cost medicine) will be regarded as core services and which will not. In practice, these allocation decisions can leave individual patient groups with less than ideal management, especially when the illness in question is rare and the medicine which is known to deliver the best treatment outcome is very expensive (216).

Economic analysis

The discipline of economics aims to provide rational and coherent grounds for making choices between alternative uses for resources when those resources are limited but the wants and demands of potential users of the resources are unlimited (217, 218). Drummond et al. treated the terms "economic evaluation" and "efficiency evaluation" as equivalent, so that the question to be answered by economic evaluation is: how great is the benefit gained by the RA needed, compared with the benefit that might be gained by allocating the same amount of resources to other programs? (219). Before this question can be answered, they suggested, the service or program or intervention must be shown to be *efficacious* (has the desired effect on some defined health outcome in a studied population), *effective* (does more good than harm overall when it is employed in the whole population for whom it is intended), and *accessible* to all of those who might benefit (219). Questions of access were addressed in section 1.9, and the methods and criteria for assessing the efficacy and effectiveness of clinical interventions and healthcare programs are described in texts such as Guyatt and Rennie (2008) (215) and Muir Gray (2009) (220, 221).

Palmer and Ho (2008) defined three types of efficiency (218):

- *Allocative efficiency* – the extent to which a distribution of limited resources among health programs maximises overall benefit in terms of improvement of health outcomes of the population to be served by those resources;
- *Technical efficiency* – the ratio of the value (in dollar terms) of the outputs of a health service to the cost of providing that service; and
- *Economic efficiency* – this refers to Pareto efficiency. A Pareto efficient distribution of resources is one in which no-one could be made better off by reallocation of resources without someone else being made worse off. A Pareto-efficient distribution does not necessarily maximise overall benefit and is not necessarily technically efficient.

Economic evaluation assumes that individuals are the best judges of their own overall good (a flawed assumption in the case of non-competent persons, including children). Even parents are not necessarily the best judges of the overall good of a child (148) (see section 1.13).

Types of economic analysis

Cost-effectiveness analysis

In cost-effectiveness analysis, the costs and desired outcomes of alternative programs are compared. For example, the dollar cost per year of life saved or per patient cured or per mm Hg average reduction in blood pressure by each of the programs might be compared (219). This method

avoids expressing the desired outcome in terms of money (218). An intervention or program that is found to be more cost-effective than an alternative one may not necessarily be efficient (i.e. the ratio of cost in monetary terms to outcome expressed in monetary terms is not necessarily greater than or equal to one) (218).

Cost-benefit analysis

A cost-benefit analysis (CBA) measures the ratio of the benefit of an intervention, in dollar terms, to its cost when both are discounted to present values (218). In theory, a CBA can be used to evaluate a single intervention or program or to compare qualitatively different programs (219).

When it is necessary to compare interventions or programs that have qualitatively different outcomes (e.g. years without dialysis for a renal failure management program, versus wheeze-free days per year for an asthma treatment program), the value of those outcomes to the potential beneficiaries must be expressed in terms common to both. In CBA, the value of the outcome is expressed in monetary terms. In these circumstances, the value of an outcome (e.g. gain of one year of life) is ascertained by a willingness-to-pay survey of the relevant population. To generalise the results of such a survey to the whole population, one would have to assume that the beliefs and the social and financial circumstances and the interaction of these in the whole population was represented in the sample. This would be extremely difficult to achieve in practice (222).

Using CBAs in healthcare decision-making implies that all costs and all benefits of the program or intervention are known and can be expressed in monetary terms. There are several problems with this assumption: first, not all costs and not all benefits can be foreseen. Even when they can be foreseen, people are often unwilling to put dollar values on desired outcomes, especially if they involve years of survival (222). This unwillingness is likely to be even greater when a parent is asked to put a dollar value on an outcome affecting a child. Second, some programs or interventions may give more benefit to some individuals than to others, or may deny some benefit to others (218).

Cost-utility analysis

Cost-utility analysis is a subset of cost-benefit analysis, in which utility is expressed, not in monetary terms, but in terms of some other indicator of benefit, such as years of life saved or quality-adjusted life years (QALYs) saved. Whereas in cost-effectiveness analysis, the benefit is a single program-specific measurement (e.g. days per year of school loss saved by asthma prophylaxis) and is not weighted by its value to the patient, in CUA the benefit is generic and is weighted according to the benefit experienced by individual patients (219).

There are several standard systems for adjusting for quality of life (223), more recent ones being the Health Utility Index and Euro-Qol-5D (224). QALYs are weighted on a scale from zero (death) to 1 (perfect health). Individuals are asked in a survey to rank states of health according to their preferences for those states. Typically, the participants in those surveys are health workers or medical students rather than sufferers from the illnesses being assessed (218). This means that the preferences are theoretical rather than based on actual experience of the health states being ranked. Furthermore, when the health state rankings are based on a willingness-to-pay method, they can be criticised as being influenced by the financial circumstances of the individuals surveyed. When the rankings are based on time trade-off (how many years in one health state is equivalent to a year in another health state), the rankings may be a reflection of attitudes to death rather than attitudes to the health states in question (218, 225).

Cost-utility analysis may be appropriately used for decision-making about RA when health-related quality of life is an important outcome of the programs being compared, or when the programs affect both mortality and morbidity. It can also be suitable when the programs have different types of outcome that ultimately affect longevity or quality of survival, or when a limited budget must be reallocated among disparate programs (e.g. in Program Budgeting and Margin Analysis (PBMA), see below) (219).

Estimation of QALYs saved by an intervention or program depends on evidence from clinical studies, of which there is a hierarchy of reliability with systematic reviews and meta-analysis at its apex (221). The collection of data and the performance and publication of trials takes time, however, so that by the time the results of a systematic review are published, new techniques or treatments or programs have often produced results better than, or different from, those reported in the review of trials performed some years previously.

Clinical studies (and especially randomised controlled trials – the most reliable form of individual trial) specify a particular group of patients that was studied: the results of the study can only be assumed to apply to other patients of that specification (e.g. children from one month to five years of age with pneumonia due to Gram-positive organisms, but not to older or younger children or those with pneumonia due to other types of organism). Healthcare allocation decisions, on the other hand, tend to involve wider age ranges and specifications of illness. The use of the highly specific conclusions of clinical trials performed years before as evidence to support the decision to allocate healthcare resources among larger, more heterogeneous groups of patients, can be questionable.

Utility estimated in this way ignores other sources of utility for many individuals. For example, a program that saves five life years in a near-perfect state of health but requires the individual to

sacrifice training, career or contact with friends and family over a long period may be estimated by strict CUA as delivering five QALYs, whereas in fact the increment in utility experienced by that individual may be very small. If a program delivers numerous QALYs to its beneficiaries but causes great health inequity over the whole population, the measured gain in QALYs may not accurately reflect an increase in utility – even for its direct beneficiaries – if the true utility of those beneficiaries requires that they know that the health system is equitable (218).

League tables of QALYs have been published (226, 227) in which services and interventions are listed in decreasing order of QALYs that each has been shown to produce. In theory, a health service could elect to fund only those services which fell above some cut-off level of QALY. There are severe limits to the reliability of these tables, however, because they are dependent on summary statistics (and are therefore a poor guide to the case of the individual patient) and the QALYs on which they are based are subject to wide variations due to combinations of client factors (e.g. age, gender, stage of illness, different valuations of health states), service factors (e.g. location of service, experience of the clinicians involved, number of cases treated) and study factors (years of the study, discount rates, nature of the programs which were compared and heterogeneity of the methods used in the studies) (226, 227). For these reasons, it has been suggested that healthcare decision-makers use league tables with caution (218).

The use of cost-benefit and cost-utility analyses in healthcare decision-making by governments has been strongly advocated in Australia (223, 228, 229), the UK (230) (where the National Institute for Health and Clinical Excellence (NICE) and the NHS use QALYs to establish priorities in healthcare (231)) and elsewhere (232, 233). In Australia, for example, the PBAC has required pharmaceutical companies to establish the cost-effectiveness of drugs for acceptance into the PBS since 1993 (234).

Qualitative studies in Australia, Canada, the UK and Europe have found that while healthcare decision-makers at macro (i.e. national, state/province or area health authority) level believed that economic evaluation of programs and interventions was important and potentially useful, it was not much used in practice(235-239). The reasons given included timeliness (allocation decisions must often be made quickly, before the results of a commissioned study can be available); lack of studies relevant to the allocation decision; mistrust of the available studies because of the assumptions made, faulty methodology or perceived sponsorship bias; difficulty moving between budgets; and belief that other considerations such as cost containment, political feasibility and equity were more important than cost-effectiveness(235, 238, 240-242).

In 2007, Chantale Lessard pointed out that the need for clear-cut evidence to support healthcare decision-making conflicts with the uncertainty of effects of macro-scale RA decisions and the fact

that the circumstances, health state, interests, relationships and preferences of any individual are unique (237). Inevitably, any RA decision must be adaptable and able to deal with the complex and unpredictable consequences, to individuals and to the resource allocating body, of its implementation (243).

Program Budgeting and Marginal Analysis

Program Budgeting and Marginal Analysis is a method of reallocating a limited budget among competing programs, with the aim of increasing overall benefit to the population served by that budget. The first questions addressed in using PBMA are: what total resources are available and how are they being spent at present (i.e. what is the current pattern of program budgeting)? (244). Then the most promising programs requiring more funding are identified, and their probable effectiveness estimated. Finally (in marginal analysis), the investigator looks for savings which could be made without overall loss of effectiveness, in resources currently allocated to programs, so that those resources could be reallocated to the under-funded programs (244). For PBMA to work as intended, there must be disinvestment in some programs or interventions which more recent studies have shown to be ineffective (245, 246).

Provided the criteria for proposing change are stated at the outset and are agreed upon by decision-makers and other stakeholders, considerations other than those of pure economic evaluation can contribute to reallocation decisions. For example, overall health gain, improvement in access or in equity, availability of suitable staff, sustainability and integration with other healthcare systems may be considered (247).

Multiple national health services, including in the UK, Canada, New Zealand and Australia, have used PBMA or one of its variants (244, 248). The principal barrier to its more widespread use has been the difficulty of disinvestment in less-effective programs or interventions. Clinician input is needed to identify candidate programs or interventions (such as lung reduction surgery for severe emphysema or corticosteroids for head injury) (246) for disinvestment. In general, “passive” disinvestment in programs or interventions which are no longer used or which have been replaced by newer techniques is more likely to be successful than “active” disinvestment, to which there are barriers including resistance by clinicians and patients who have benefited in some way from the program, by institutions such as hospitals whose existence depends partly on continuation of the program, or by suppliers of drugs or equipment (246).

Accountability for Reasonableness

Accountability for Reasonableness (A4R) is more a set of legitimising conditions for allocation decisions made by other means (such as PBMA) than a process by which such decisions can be made. A4R aims to identify those reasons which everyone should agree upon and should be considered when setting priorities in healthcare or making RA decisions (249).

Daniels and Sabin (1997) set out the following conditions for legitimate decision-making by an institution:

- decisions and their rationale about limits to care must be publicly accessible;
- the rationale must be on the grounds of relevant evidence, reasons and principles that are accepted by fair-minded people; and
- there must be mechanisms for appeal and dispute resolution and the process must be publicly regulated. (250)

Researchers have criticised A4R as a means of ensuring fairness in decision-making. In particular, Kieslich and Littlejohns pointed out that achieving fairness of process does not necessarily mean that a fair healthcare RA outcome will be reached (251), and Lauridsen noted that the A4R framework demands that reasons and principles used in reaching a decision be relevant, without specifying how to distinguish between those that are relevant and those that are not (252).

Singer et al. (2000) found, in a qualitative study of two RA committees in Canada, that variants of the A4R principles were in operation in decision-making by the committees and that efforts were made to achieve procedural fairness. For example, decision-making was transparent within the committee, but "not widely publicised outside the committee." Conflicts of interest were acknowledged (though not eliminated); honesty was maintained and consensus built, but without mention of appeal mechanisms, (public) dispute resolution or public regulation of the decision-making process (253). Similarly, in examining the allocation decision-making processes used by NICE, which professes to use the principles of A4R in its decisions, Schlander found that although NICE employs standardised decision-making methods and publishes relevant documents on its website, the cost-utility methods used were not very transparent, nor were the cost-per-QALY reasons plausible, and the revisions and appeals process was somewhat restrictive (254). Studies of the acceptability (by beneficiaries/victims) of allocation decisions have found that when the emphasis is on fairness of process, the decision-making mechanism has become more accepted with the passage of time, but that the existence of an appeal and review mechanism is important to acceptance by stakeholders and the public(255).

2.5 How is healthcare rationed in Australia?

Appendix 4 describes the evolution of the involvement of Australian governments in the provision of healthcare resources.

Federal Government

The Australian Constitution stipulates that all Federal Government revenue be collected in one Consolidated Revenue Fund, and that all monies paid for Government activities (such as provision of health services) be disbursed from that fund(256). According to Sections 81 and 83 of the Australian Constitution, drawing of any monies from the Consolidated Revenue Fund for any purpose requires an Act of Parliament. In other words, the ultimate decision-maker about any large-scale funding of healthcare resources by the Federal Government is the Federal Parliament. Annual appropriations, authorised by two Appropriations Bills, account for about 25% of Government expenditure and provide for the normal running of government activity plus new activities and capital works(256). Special appropriations, authorised by Special Appropriations Bills which specify the purpose (such as nominated programs) for which the amount of money is to be used, account for 75% of government expenditure(256).

The content of the Appropriations Bills and the nature of the programs (including healthcare programs) they support are determined by cabinet. Departmental officials offer detailed advice to cabinet to inform decisions about content of the Appropriations Bills, and hence about what programs will be funded and about which groups in the population will benefit from the expenditure which the Bills prescribe, but it is the members of cabinet, deciding on programs which carry out the policies of the political party currently in power, who decide the content of Appropriations Bills. Most allocation decisions then, are made during the Budget process or during the production of the Mid-Year Economic and Fiscal Outlook, or agreed upon during Council of Australian Governments (COAG) meetings(256).

State Government

The states differ in the manner in which revenue is accessed and distributed, and the role of their health minister in the distribution of the Department's budget. In NSW, for example, the State Budget and the accompanying Budget Paper 4 (an Appropriation Bill) are produced on the detailed advice of the executive (in particular, by the elected members of cabinet who are, in turn, advised by the non-elected officials of each department) and allocate a fixed total budget to each department. New cabinet policy decisions may require extra funding allocations during the year (257). These extra allocations include additional Appropriations Bills, Treasurer's Advances (within the

Appropriation Act), Exigencies (for unforeseen and urgent expenses), transfers between programs, and supplementations with offsetting savings within a department (257).

2.6 What is the role of ethics in healthcare resource allocation by governments and their agencies?

The contention that governments only exist and retain powers to govern by the consent of those governed dates from the Renaissance or earlier. It was expressed by John Locke in his *Second Treatise of Government* (258) and appears in the 1776 Declaration of Independence of the United States of America (259) and in Article 21 of the 1948 United Nations Universal Declaration of Human Rights, which states that "the will of the people shall be the basis of the authority of government … " (260). Furthermore, Locke argued, since the only legitimate powers of civil government are those which individual members of the society cede to the government, a legitimate government is obliged to govern justly (258) and in the interests of the society. Locke argued that in the state of nature (into which all people are born, antecedent to society and government) all individuals have freedom to act as they think fit, and to keep, or dispose of, their possessions as they think fit. These powers are only ceded to government, in whole or in part, by all members of a society, if there is tacit agreement by members of the society that cession of such powers by all confers advantages to all (258). For agreement to be reached, there must be some achievement of mutual advantage from the cession of powers. This means that the concepts of justice and the interests of the society must be actively considered in all legitimate government's decision-making. Governments of Western democracies such as Australia, the US, UK and most European countries, which regard their legitimacy as resting on the consent of the governed, are bound by this principle. Justice and the interests of the society are ethical concepts, so inevitably, *some* conception by government and its functionaries of the good and of a just distribution of benefits must be a part of any decision on RA. What that conception might be is the subject of this thesis. (Justice and other ethical principles which might guide decisions about how healthcare resources are allocated are discussed in Chapter 7.)

There is widespread agreement among authors that ethical principles should be considered in decisions about the allocation of healthcare resources (157, 261-265). When it was first introduced by the NHS RAWP in the UK in 1976, funding according to an allocation formula (see section 2.4) was thought to be "value-neutral, objective and pragmatic" (266), but in fact the choice of variables included in the formula, the weighting given to each and the choice of criteria by which the effectiveness of the service is judged all reflect subjective choices, made according to some prior set

of values (266). Different choices, reflecting different moral values, would produce different allocation formulae and hence different patterns of RA.

A wide range of meta-ethical principles has been advocated as suitable to guide decisions on healthcare RA, from libertarian (267) to rights (268, 269), equity (270-272), justice (273, 274), utilitarian (224, 275-278) and communitarian (175, 279-282). These are considered in more detail in Chapter 7. The following section examines the role which ethical principles have been found to play in healthcare RA in practice.

2.7 What is the role of ethical principles in practical decision-making?

When individuals make decisions, the best evidence about the role of ethical principles is the individual's testimony, although many factors (such as quality of memory, desire to be seen to conform to department policy, or desire to give the interviewer the viewpoint that they appear to expect) may lead to a discrepancy between the interviewee's account and what actually happens or happened. In practice, however, most healthcare RA decisions are made by groups or committees, rather than by individuals (283). While the proceedings of such groups or networks or committees may be transparent (e.g. the proposal to introduce capitation funding in the NHS (England) (284)), the committees or networks consist of individuals, each of whom has her own knowledge, experience and motivations, so that the testimony of those individuals may be as relevant as the published proceedings of the decision-making group to answering questions about the role of ethical principles in the decision-making process.

When healthcare resources are allocated to sub-units of a healthcare organisation by a transparent funding formula which takes into account perceived need, such as the allocation formulae used in the NHS (see section 2.4) and previously in NSW, the key decisions are which variables to include in the formula and the weighting to assign to each. When such funding formulae are not used (e.g. in the Victorian and the Australian Departments of Health), decisions on funding priorities are made about individual programs, geographical regions and patient groups. To examine the evidence on the way in which decision-makers assign priorities to a list of healthcare resources which may affect rural children published and grey literature from Australian sources and other sources relevant to RA decision-making in Australia was reviewed. The methods and results of that review are described in the next chapter.

Chapter 3: Literature review: How healthcare resource allocation decisions are made in practice

The preceding chapters show that health outcomes of rural children are less favourable than those of urban children and that this health disadvantage increases with remoteness. They also show that the moral status of children differs from that of adults because of their immaturity and dependence on adults. A range of ethical principles could guide the allocation of healthcare resources to improve health outcomes for rural children (discussed in Chapter 7), but to understand how this might be done it is first necessary to understand how RA decisions are made in practice. This chapter contains a detailed review of the published and grey literature on healthcare RA decision-making.

3.1 Coverage of the topic in the literature

Although there is an extensive literature on arguments for change in the way healthcare RA decisions are made, including a few articles which argue for change in RA to children, the literature describing the process of RA decision-making in practice is sparse. When this review was conducted, there were no articles describing the process of RA decision-making which affects children, nor the ethical principles which guide that process, and none describing the process of RA decision-making which affects rural people. This apparent lacuna in the published literature makes the current investigation the more important, given the particular moral status of dependent children, discussed in section 1.13.

Advocacy for particular guiding principles for healthcare resource allocation decision-making

There is a large literature on the ways in which RA decision-making should be conducted (see section 2.4 for an overview of methods of allocation) and on the ways in which particular population groups, such as rural persons (285-288) or children (289-291), should be treated in RA decision-making. The next section briefly describes the literature which advocates for particular modes of decision-making about healthcare RA, including government guidelines on the role of particular ethical principles in decision-making. Some of these articles are exploratory (292), describing patterns of RA. A sub-section of this literature consists of government documents which aim to set guidelines (including ethical guidelines) for future government decision-making. Some of these offer quite general guidelines: for example, the Australian Department of Health and Ageing report *Primary Health Care Reform in Australia 2009* pointed out that "not all people are receiving equitable levels of primary healthcare services due to where they live, their ability to pay or their health condition" (293), and

asserted an over-arching requirement that service provision be efficient and cost-effective (293). This paper offered general guidance for policy reform to improve the current situation: “reduce the current fragmentation of service delivery and funding arrangements”; “support local flexibility” and possibly enhance the role of regional primary care organisations (293).

Other government documents offer more concrete guidance on ways to implement particular approaches to policy formation. In 2007, the Australian Senate Standing Committee on Community Affairs published a report titled *Highway to health: better access for rural, regional and remote patients* (294). This document described the difficulties of people in rural and remote areas in obtaining access to necessary healthcare and made detailed recommendations for improving transport arrangements for patients and carers to regional or urban healthcare facilities in order to improve equity and reduce rural disadvantage in health outcomes, and for monitoring the performance of those arrangements. Similarly, the 2004 NSW Health document *In All Fairness* (295), the development of which was described by Hyde (2007) (296) (see section 3.8), gives guidance in some detail, as well as some practical examples, of ways in which equity might be incorporated into all policy and administrative decisions by officials of the Department. It details ways in which the Department should coordinate its activities with those of other NSW Government departments to ameliorate health inequalities due to social determinants of health. The limited success of this document in achieving healthcare equity in practice, however, was described several years later by Kirigia(265) (see section 3.4).

Principles and guidelines for resource allocation decision-making in the English NHS

The exemplars of transparent, principle-guided decision-making in macro-allocation of resources in health systems similar to the Australian one come mainly from the UK. For example, the English NICE provides evidence-based advice on healthcare treatments to healthcare providers, to institutions such as hospitals and to government instrumentalities such as the English NHS. There is a wealth of descriptive documentation of the way in which NICE produces RA advice and of the principles which guide the formulation of that advice. While NICE’s charter states that “the NHS in England and Wales is legally obliged to fund and resource medicines and treatments recommended through our technology appraisal programme” and describes consultations with stakeholders and the independence and transparency of the NICE assessment process (297), NICE is *independent of government*: its role is ultimately an advisory one, and actual RA decisions are made by government departments and instrumentalities.

In 2013, the English NHS Commissioning Board published a document called *Commissioning policy: Ethical framework for priority setting and resource allocation* (298). This document set out in precise detail a set of 15 core principles which gave mandatory guidance to all RA decisions at macro, meso and to some extent micro levels within the English NHS. Principle 5 is:

> Access to services should be governed, as far as practicable, by the principle of *equal access for equal clinical need* [emphasis added]. Individual patients or groups should not be unjustifiably advantaged or disadvantaged on the basis of age, gender, sexuality, race, religion, lifestyle, occupation, social position, financial status, family status (including responsibility for dependants), intellectual / cognitive function or physical functions. There are proven links between social inequalities and inequalities in health, health needs and access to healthcare. In making commissioning decisions, *priority may be given to health services targeting the needs of sub-groups of the population who currently have poorer than average health outcomes (including morbidity and mortality) or poorer access to services* [emphasis added]. (298)

This degree of control over the incorporation of ethical principles into decision-making is feasible in a centrally-controlled, publicly funded health service such as the NHS, in which decision-making is transparent and takes place (to some extent at least) at arm's length from the political process. It appears to be less feasible in Australian jurisdictions, in which funding of healthcare comes from federal, state and private sources, and in which political influence over the allocation of funds and facilities appears to be much more considerable than is the case in England (265).

Having considered the limited literature on guidance for RA decision-making, and before examining how healthcare RA decisions are actually made, the chapter now moves to the nature of policy and some theoretical models of decision-making.

3.2 Healthcare policymaking in practice

Case reports on the process of healthcare policy decision-making are generally written by observers outside the decision-making process (299); the views of decision-makers on the decision-making process are to be found in reports of interviews with government officials (162, 216, 265, 283). There is a considerable literature on the theory of policymaking (300-303), some of which refers to healthcare policymaking in Australia (302-304) and decision theory. This large body of literature is referred to only briefly in order to explain the context of this present review; the next section gives a brief overview of models of decision-making derived from empirical observation.

Policymaking and decision-making

A *policy* is an overarching plan of an individual, an organisation or a government to perform an action or actions to deal with a problem or respond to a situation. Enacting a policy may involve making individual decisions (e.g. enacting a government policy to house all homeless people in a city may require numerous decisions about building and siting new housing and about the characteristics of that housing). Anderson described these as "routine" decisions (300) to distinguish them from the decisions made by policymakers to form the policy.

A *decision* can be seen as the process of choosing one of several alternative actions (or in some cases, alternative things). Decisions may be made by individuals or by groups: within an organisation such as a government department, most healthcare RA decisions are made by groups such as advisory committees of senior bureaucrats. Several models have been proposed to describe the observed process of decision-making by individuals and groups (300, 302, 305, 306).

Rational model

According to this model, the problem is identified ("named and framed" (303)). The various objectives and sets of values (explicit or implicit) of the decision-makers are then ranked. The alternatives for action to deal with the problem are assessed in relation to the prevailing circumstances, such as the availability of funds and personnel, and the political situation, and in relation to the ranking of objectives and values. The likely consequences of adopting each of the alternatives are compared; the alternative which best fits the overall goals and values of the decision-maker is then adopted.

Several commentators have pointed out the inadequacy of this model to describe organisational decision-making in the real world (300, 303). The nature of the problem depends on how it is framed and on the point of view of the person/group that identifies the problem; for example, a high hospital admission rate for rural children with asthma could be seen as indicating inadequate primary care or an excessively low threshold for hospital admission of such children. The sets of alternative actions to deal with these two versions of the problem are very different. This model assumes more complete knowledge of necessary information and of the likely consequences of the alternatives for action than is generally available. It also assumes (often incorrectly) that the members of the decision-making group have the same objectives and values, and that these are also the objectives and values of the public on whose behalf the decision is being made (300).

Bounded rationality

Although many decision-makers may prefer to make decisions in a systematic, rational and transparent way, lack of the required information, the complexity of problems, uncertainty of outcomes and the need to decide quickly often limit their ability to do so. Consequently, decisions are made, according to this model, dependent on shared culture and ethical assumptions within the organisation, on the history of previous decision-making, and to some extent on the instinct of influential decision-makers (306). The range of available alternatives may be limited by resource (other than financial) availability and by political considerations, both within the organisation, and in the case of government departments, within the wider electorate.

Incremental model

This is a pragmatic means of deciding on the solution to a problem, in which decisions are made by a group of individuals who are prepared to compromise; it produces practicable solutions which, though not necessarily the ideal, are at least acceptable to members of the group (300). The definition of the problem, and identification of solutions are influenced by each other; only some alternatives and only the most important and relevant consequences are taken into account.

This model leads to evolution of the current situation, by small incremental changes, building on the status quo and leading to repeated reassessment and redefinition of the problem and of feasible alternative solutions, rather than to radical social change (300, 306). Agreement on incremental change is more readily achieved than agreement on major changes in policy direction, but incremental change is said to favour the more influential members of society such as health service providers or teaching hospitals (300). The incremental model is unable to explain major policy decisions which represent sudden marked changes in policy direction, such as the introduction of Medibank in Australia in 1975(178).

Garbage can model

In 2003, Kingdon (301) argued that the above models can describe part of policymaking but that they leave much unexplained. He pointed out that ideas for alternative solutions for problems can come from anywhere; they often evolve from a continuous series of earlier ideas, and it is often hard to define exactly who made the decision to present a particular solution as one of a series of alternative solutions for a problem and on what grounds.

Kingdon argued that because political considerations have a major influence on the acceptability of a solution, and because ideas for potential solutions can be seen as being in a state of perpetual evolution from earlier ideas, problems, solutions and politics should be seen as disconnected from

each other. He enlarged on Cohen's garbage can model of organisational choice (305), in which a loose and changing group of decision-makers without consistent, shared goals make decisions within an organisation. In Cohen's model, participants, choices looking for problems, and the problems to which they might be the solution, float in and out of the organisation. What is critical in this model is the meaning that the problem and the solution have for the participants at a particular time, and the timing of their presentation to the participants, relative to other considerations such as feasibility and political realities (301, 303, 305). An example of this form of decision-making might be the Australian Government's decision to allocate funds for construction of new school buildings and for installation of domestic roof insulation to stimulate the national economy in response to the global financial crisis in 2008–09(307).

After this brief overview of the normative literature on guidelines for decision-making on the allocation of healthcare resources, the focus turns to what happens in practice.

3.3 Aim of the literature review

To find and critically analyse articles and documents from the published literature and the grey literature which discuss the role ethical principles play in the making of healthcare resource allocation decisions which affect rural children.

The review included only articles which refer to the health systems of Australia and New Zealand, Canada and the UK, because these health systems and political and administrative structures are the most similar to Australia's. For that reason, articles which referred mainly to the health systems of the US or the countries of continental Europe were excluded. In order for the search to be manageable in the time available, and due to the candidate's interest in contemporary decision-making in government health organisations, rather than in historical decision-making or historical health delivery structures, only articles published since 1990 were included. Some older articles found by hand-searching bibliographies were included because of the light they shed on current RA.

3.4 Search method

Database search

A thesaurus search of Medline, Cinahl, Embase and EBSCO Academic Search Complete databases was followed with a keyword search of PubMed and Informit databases, as well as Web of Science and Political Science Complete. Details of the search terms used in these searches can be found in Appendix 5 and the results of the search can be seen in Figure 1.

Sieve 1

After each search (database or table of contents), articles which referred only to the US, continental European countries or developing countries were excluded (Figure 1).

Sieve 2

The titles and abstracts of articles remaining after application of Sieve 1 were examined, and only articles which discussed the process of RA were retained (Figure 1).

Searching these databases yielded 785 references. Application of sieve 1 yielded 49 references. Examination of the abstracts of these articles (sieve 2) yielded 20 references; examination of their text revealed only four relevant to this search.

Manual search of journals' tables of contents

The tables of contents of journals in which relevant articles were found were searched manually. Issues inspected dated from 1990 to the latest available at the date of search (27 December 2014). Appendix 6 contains a list of these journals.

Manual searching yielded 95 new references; examination of their abstracts yielded 18 relevant to the current search. When the full text of the 18 articles was examined, only six were found to address questions closely related to the topic of this search. These articles are discussed in more detail, together with six further articles and two book chapters found by examining the bibliographies of relevant articles and by consulting experts in the field, and the four articles found through database searches.

Figure 1 summarises the literature search process and the selection of relevant articles. Eighteen articles were relevant to the search, although none was found that matched the search topic exactly; Table 8 lists their characteristics.

FIGURE 1 FLOWCHART OF THE RESULTS OF THE LITERATURE SEARCH

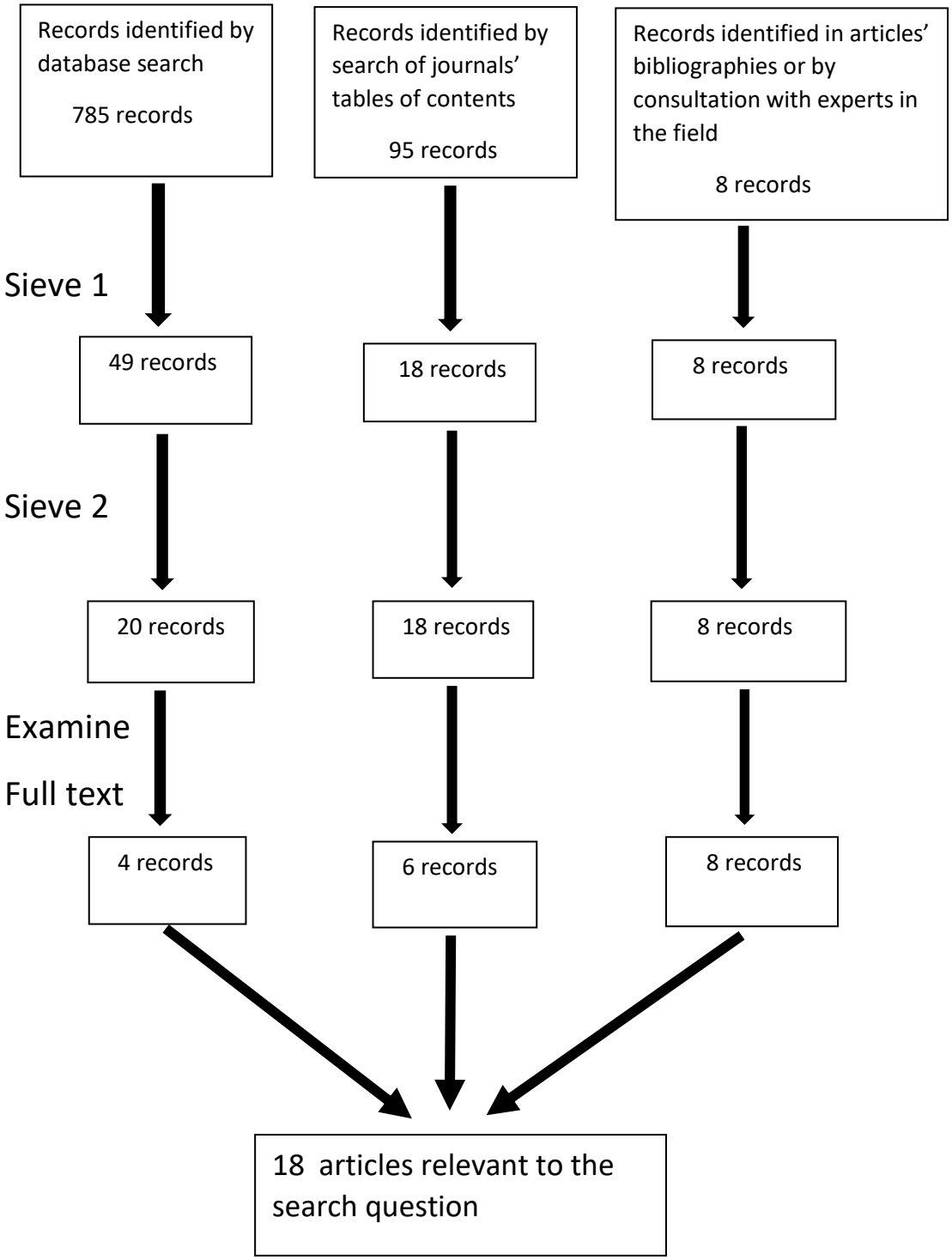


Table 8 The 18 articles most relevant to the search topic, grouped by category

Author/s	Year	Journal	Australian or International	Category	Relevance to this topic	Quality of evidence (score out of 10)
Galani and Rutten (308)	2008	Curr Med Res Opinion	International	Systematic review	Good	5
Guindo et al. (264)	2012	Effectiveness and Resource Allocation	International	Systematic review	Good	7
Ham and Coulter (162)	2001	J Health Serv Res & Policy	International	Narrative review	Good	9
Hicks (266)	1985	Milbank Memorial Fund Quarterly: Health & Society	Australian	Narrative review	Moderate	7
Keren et al. (309)	2004	Pharmacoeconomics	International	Narrative review	Moderate	8
Lewis (303)	2003	Book chapter	Australian	Narrative review	Good	9
Lin (302)	2003	Book chapter	Australian	Narrative review	Good	7
Baghbanian et al. (283)	2012	Aust Health Rev	Australian	Qualitative	Good	6
Gallego et al. (310)	2008	Aust Health Rev	Australian	Qualitative	Moderate	8
Gallego et al. (216)	2009	Health Policy	Australian	Qualitative	Poor	8
Kirigia(265)	2009	PhD Thesis UNSW	Australian	Qualitative	Good	7
Nord et al. (311)	1995b	Health Policy	Australian	Qualitative	Moderate	8
Alexander and Hicks (312)	1998	Aust Health Rev	Australian	Case study	Poor	3
Hyde (296)	2007	Asia Pacific J Health Management	Australian	Case study	Moderate	6
Baghbanian et al. (235)	2011	Aust Health Rev	Australian	Survey	Poor	6
McKie and Richardson (262)	2011	Health Econ Policy & Law	Australian	Survey	Moderate	6
Nord et al. (313)	1995a	Soc Sci Med	Australian	Survey	Moderate	6
Ross (236)	1995	Health Policy	Australian	Survey	Moderate	4

Appraisal tools used with each category of article

The 18 articles were assessed for relevance, quality of evidence and strength of the arguments presented, using appraisal tools appropriate to each category of document. The criteria used in each appraisal tool are set out in Appendix 7. Table 8 presents a summary of relevance to the topic and quality of the evidence (scored out of 10 using the relevant appraisal tool, and taking into account the fact that some criteria in each appraisal tool are more important than others).

The findings of the literature search are described under the following 13 headings:

- How do Australian healthcare decision-makers describe the process of decision-making?
- The Australian experience with capitation funding
- Constraints on the achievement of equity in resource allocation decision-making in NSW
- A case study of a consultation process in the formulation of policy
- The views of international decision-makers on how resource allocation decisions are made
- The meta-structure of healthcare resource allocation decision-making
- What is the role of economic evaluation in resource allocation decision-making in Australia?
- The use of economic evaluation in allocating healthcare resources to children
- The views of the Australian public on economic evaluation in healthcare resource allocation
- Public participation in healthcare resource allocation decision-making
- Should the views of the public be taken into account?
- How should the community be consulted?
- An Australian example of public consultation in priority-setting among healthcare programs.

In the absence of literature which directly addressed the topic of the search, the subject headings were dictated by the existing literature which addressed issues *around* the search topic but not directly *on* the topic.

3.5 How do Australian healthcare decision-makers describe the process of decision-making?

Several articles in the published literature describe the grounds on which decision-makers decide on RA (265, 310), and numerous articles and books recommend one method or another of making such decisions (314, 315) or describe the role of criteria for making such decisions (such as research evidence (242, 316) or various ethical criteria (265, 270)), or recommend criteria for making healthcare RA decisions (228, 263, 275). Few articles describe the actual process of decision-making

in the words of the decision-makers. One article which does describe the process was published by Baghbanian et al. in 2012 (283), and is discussed below.

A model of the decision-making process: an Australian perspective

Baghbanian and colleagues performed a mixed-methods investigation of titled "Adaptive decision-making: how Australian healthcare managers decide" (283). They invited 378 healthcare administrators to complete an online questionnaire on the subject of the use of economic analysis in their RA decisions. Ninety-one participants completed the questionnaire (a response rate of 24%). (This response rate is very low, but is close to those reported in similar studies in Australia (262, 313); note also that when Keeter et al. compared "standard" and "rigorous" surveys with response rates of 25% and 50% respectively, they found that the results were statistically indistinguishable (317).) The results of the survey are described in Baghbanian et al. (2011) (235). From these 91 participants, a sub-sample of 25 were willing to be interviewed. These 25 were healthcare administrators at various levels of seniority in the Australian and NSW Departments of Health, who had some responsibility for the allocation of financial resources for healthcare (283). The results of those interviews and analysis of the results of the mixed-methods study were published in Baghbanian 2012(283).

The authors gave a thorough description of their research methods (including the collection, analysis and interpretation of data), which were entirely appropriate to the topic under investigation. They claimed to use a constructivist grounded theory approach, but although they noted that this approach "sees both data and analysis as created from shared experiences and relationships with participants," there is no mention in the paper of the authors' roles, either culturally or in relation to the participants.

Participants in this study all reported that decisions were made by groups or committees; none reported decision-making by individuals. This appeared to be because enactment of decisions required the cooperation of others and agreement on the existence and nature of the problem. Baghbanian et al. noted:

> Participants reported that a specific decision was not simply a matter of an individual actor's knowledge, but incorporated multiple human and non-human factors in a specific situation. The described a distributed, collaborative decision-making network with mutual goals, but with different processes employed in each part of the network, and for different decision-making tasks. (283)

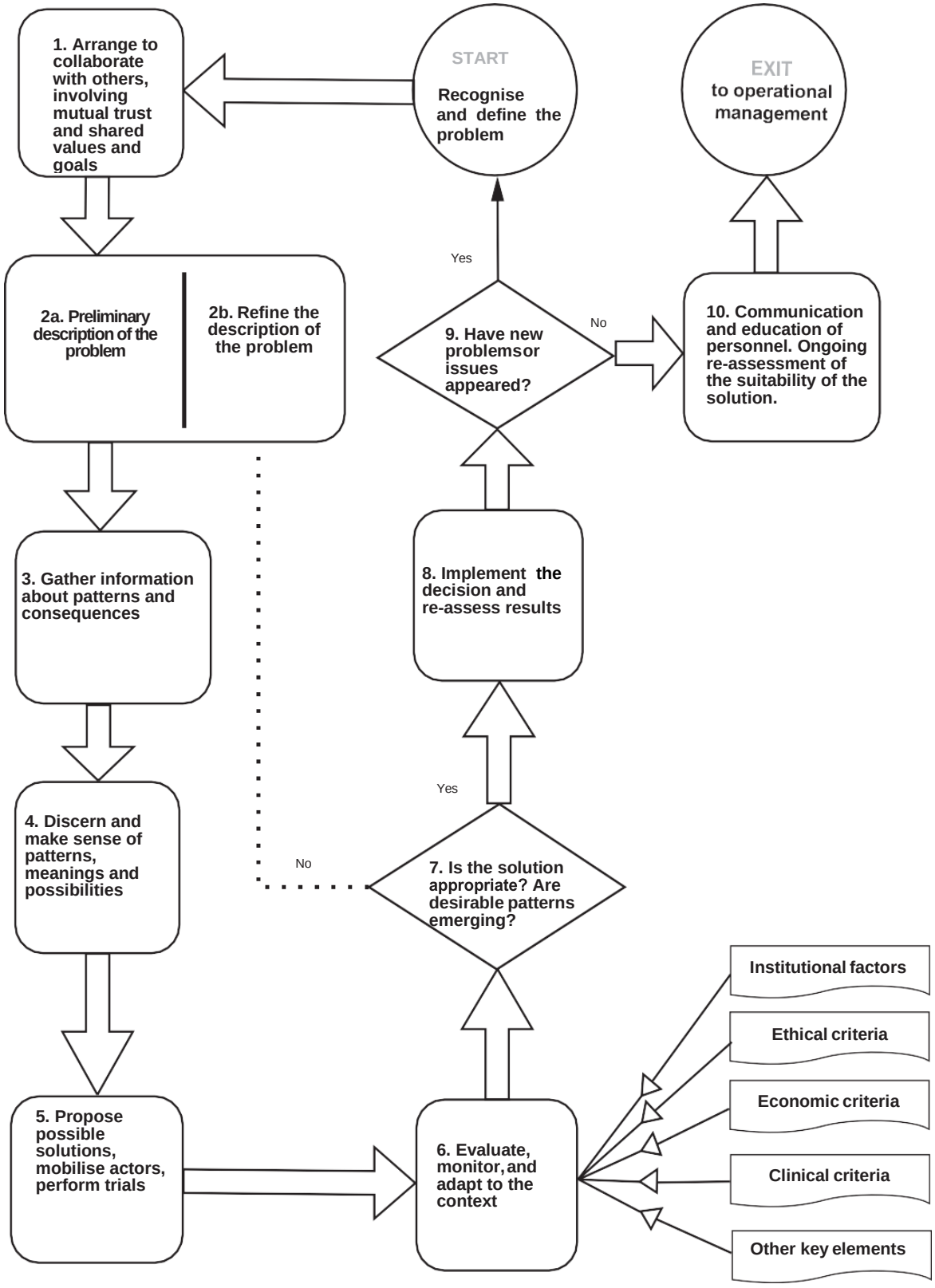
The participants reported dependence on the knowledge and experience of the decision-making group, as well as on outside advisers and stakeholders.

Baghbanian et al. noted that methods of decision-making appeared to vary widely across the health system, depending on the seniority, experience and knowledge of the personnel involved, the power structure of the organisational unit where the decision took place, and particularly the context. Components of that context, according to the interviewees, included political considerations, policy directives (such as delegation manuals and procedural guidelines), ethical considerations, knowledge shared between decision-makers, economic considerations and constraints, and 'institutional complexity'. One interviewee pointed out that the impetus to change a policy in the first place came sometimes from the community or from politicians, sometimes from a perceived need, and sometimes from an accumulation of evidence that policy change was required.

The authors pointed out that despite repeated calls for healthcare RA to be based on the findings of scientific research ("what works") and economic evaluations, these are limited in their impact on decision-making, since scientific research tends to be reductionist (limited in the applicability of its findings by the need to eliminate confounding variables) and neither scientific nor economic research can take sufficient account of the particular context in which an individual RA decision is taken. Participants in this study noted that most of the problems for which they had to find solutions involved incomplete information and 'significant unknowns', but in each case, some solution had to be (and was) found.

Having gathered evidence reported by their interviewees, the authors searched for a suitable model of decision-making that would explain their findings. They examined and rejected the linear rationalist model and its variants (which did not reflect the "varied, social and contextual nature of decision-making" (283) and the more diffuse garbage can model (see section 3.2) which "becomes less sensitive to changes in task complexity as the number of tasks needed to be completed increases" (283). They found that a process called adaptive decision-making fitted their findings better than any of the models usually described in healthcare, although the authors did not explain how they reached that conclusion. Figure 2 illustrates the process of adaptive decision-making proposed by Baghbanian et al. to best explain decision-making about healthcare RA as described by their interviewees.

FIGURE 2 THE PROCESS OF ADAPTIVE DECISION-MAKING



Adapted from Baghbanian et al. (2012) (283)

This model, derived from the environmental and urban planning literature (318, 319), appears to summarise the phenomenon of decision-making described by Baghbanian's participants and those of Kirigia (see below) (265) better than either of the Rational models. The latter make the decision-making process appear unrealistically clear, purposive, monothematic and divorced from its political and cultural environment. Baghbanian et al.'s adaptive decision-making model also describes those phenomena better than the garbage can model, which appears to offer so indistinct an outline of the process that it could describe almost any combination of observed phenomena in decision-making, thereby rendering it less useful for analysis of the process.

Baghbanian's participants made particular mention of the way in which alternative solutions to a problem were trialled for efficacy, and the results of the trials assessed using the expertise of those involved in the decision process or that of outside advisers. Only after these trials were assessed (according to these officials) was formal economic evaluation performed, followed by examination of questions of equity and access (283).

Decisions on RA by government departments are subject to public scrutiny and are more defensible when the basis on which decisions are made is consistent and transparent. One method of allocating a limited health budget among geographical areas according to the needs of each area is funding according to a consistent distribution formula (capitation) funding. In Australia, capitation funding has been used in NSW and to a lesser extent, in South Australia (266).

3.6 The Australian experience with capitation funding

Capitation funding, described in section 2.4, is intended to distribute funds among the geographical regions of a jurisdiction according to the healthcare needs of their populations. In 1985, Hicks published a narrative review of the history of capitation funding in Australia to that date, its most advanced development being in NSW. Hicks pointed out the financial and resource (hospital beds per capita) inequality which existed between geographical regions in NSW before the introduction of capitation funding, and described the derivation of the NSW formula from that used in the UK NHS (section 2.4) (266). Hicks noted the difficulties inherent in transition from the previous inequitable funding distribution to needs-based capitation funding; in particular, the problem of a rapid reduction in funds to the inner Sydney regions, where most of the State's expensive tertiary hospitals are located, to poorly funded regions such as the Illawarra.

Hicks noted the simplicity of the NSW funding formula in existence at that time compared with the possibly more effective (at distributing funds according to real needs) NHS version. He was particularly critical of the dependence of the formula on standardised mortality rates as a proxy for

morbidity, rather than using epidemiological data on morbidity, noting that many medical conditions cause severe, prolonged and debilitating illness without necessarily causing death. He also criticised the concept of capitation funding as value-neutral, noting that capitation (and any other manner of allocating healthcare funding) will depend on "a prior judgement, usually unstated, about what criterion will be used as a test of the effectiveness of a health service." Such criteria might be economic effectiveness, overall health maximisation, equal access to healthcare, or equality of death rates across regions (266).

It should be noted that the NSW Resource Distribution Formula (RDF) evolved over the 30 years from its introduction in 1981–82 until it was abandoned in 2012–13 in favour of a combination of activity-based funding and block funding of individual programs (320). Kirigia (2009) published a critique of the RDF as it then existed, and of its success in achieving its avowed aim of healthcare equity (265), described below.

3.7 Constraints on the achievement of equity in resource allocation decision-making in NSW

In a PhD thesis submitted to the University of NSW in 2009, Kirigia (265) reported the results of a mixed-methods study which aimed to determine whether the NSW Health RDF, used at that time to distribute funds among the (geographically-based) NSW AHSs, had achieved equity in the distribution of healthcare resources and whether this was reflected in equality of access to financial resources within individual AHSs. In the course of these interviews, participants discussed the influences on their decision-making, and in particular, constraints on the extent to which they were able to make decisions about RA to achieve equity. The findings of this thesis are highly relevant to the argument herein, in that they illustrate where discretion to make equity-related RA decisions is located in a state health department, even one as decentralised as NSW Health. Kirigia discussed the bureaucratic structure and the decision-making apparatus of NSW (where the current research was conducted) in some detail. Although Kirigia's study focused on the degree to which equity was achieved in practice, its relevance for the current literature review lies mainly in her participants' descriptions of the limits on their discretion for making decisions which might achieve the ethical goal of equity. The qualitative part of her study involved semi-structured interviews with 30 senior officials of NSW Health at head office (senior managers, policymakers and program managers) and directors of two AHSs – Greater Western AHS and Northern Sydney Central Coast AHS – as well as some patient interviews. The aim of these interviews was to elucidate the role of equity in decision-making, in view of the 2004 NSW Health and Equity Statement (295) and the fact that equity in the provision of healthcare had been an avowed aim of NSW Health for at least two decades.

Kirigia adopted financial resources as the commodity, the equitable distribution of which was to be assessed "to give the analysis a clearer and more concise focus," and defined healthcare resource equity as "equality of access to financial resources for healthcare on the basis of health needs" (265). This focus on financial resources, however, takes little account of the role of physical (e.g. hospital, clinic, health centre), organisational, educational and personnel resources in the achievement of equal access to healthcare for equal need, and does not address the issue of inequality in health outcomes. Only in the section on mapping of healthcare facilities in two AHSs with contrasting socio-economic population structures was the issue of equity in allocation of physical resources considered, and Kirigia did not examine the issue of equity of access in any detail.

Kirigia described the distribution of the NSW health budget by NSW Health to its eight AHSs in 2008–09 by three mechanisms: expenditure-based funding (allocation of funds according to the cost to the AHS of providing an episode of care, or the annual cost of operating a program required by NSW Health); casemix or output-based funding of hospitals (payment to a hospital according to the number of cases of an illness treated, weighted by the average cost to the provider of supplying an episode of care of that illness); and The Resource Allocation Formula (see section 2.4), introduced in 1993 and modelled on the UK RAWP formula of 1976 (265).

Each of the three mechanisms in theory offers an automatic mechanism of fund allocation, without offering much opportunity for decision-making *within* the formula. It was at the level of determining the nature of each funding method (e.g. whether to adopt capitation funding; which indices of need to include in the formula, and the exact fund weight to be assigned to each index) that decision-making discretion was available to Head Office managers and policy advisers. Kirigia pointed out that in 2006-7 only 26% of money spent on health in NSW was contributed by NSW Health (44% came from the federal government and 30% from private sources), and NSW Health regularly spent 70% of its budget on hospitals. In addition, as her interviewees noted, much of the remaining funding distributed by NSW Health to its AHSs is committed to health programs determined by NSW Health Head Office, leaving only a very small amount of funding which might be distributed by AHS managers in a way that might achieve funding equity.

In the interviews, managers in NSW Health Head Office who had responsibilities for allocating funds between AHSs emphasised that because the provision of hospital services had always been a principal role of NSW Health, and because the maintenance of hospital standards had always been so politically sensitive in the state, a large proportion of state-based health expenditure was devoted to episode-of-care funding of hospitals. They pointed out that state politicians had always used the provision of hospital services as a political weapon, so that there was little political will to reduce

funding of hospital services. Promises to open new hospitals or to renovate or expand existing ones were frequently used during election campaigns to attract votes, sequestering more of the limited state health budget. Similarly, established healthcare programs had support from powerful community pressure groups and healthcare providers, so disinvestment in those programs was politically and administratively very difficult. Furthermore, the managers explained, some illnesses such as heart disease received disproportionately more funding than others (such as diabetes), with consequent effects on outcomes of the less-funded services.

Kirigia noted that the dominance of hospitals over other areas of healthcare in NSW meant that historically, funds have flowed disproportionately to parts of the state which contain large numbers of hospitals (notably inner-urban areas and large regional centres). This geographical inequality in funding was exacerbated in the past by the practice of allocating funds according to the entity's spending in the previous year. This tends, according to Kirigia, to increase the ability of the entity (AHS or hospital) to treat patients, which in turn leads to more expenditure and so to more inequality in allocation of funds. One interviewee noted that recurrent hospital crises in NSW, widely reported in the media, had each time led to diversion of funds to hospitals and away from other forms of healthcare. This method of allocating healthcare resources sounds very similar to the picture of funding allocation in the pre-1970 UK NHS, described by Maynard and Ludbrook as "what you got last year plus an allowance for growth plus an allowance for scandals" (174).

Area Health Service managers, interviewed by Kirigia, reported several constraints on their ability to allocate funds in a way that improved equity. One of these was the adequacy of total funds provided by NSW Health to the AHS, given that most of those funds were already committed to hospitals or to that AHS' share of statewide programs. They also mentioned that guidance in RA at AHS level and systems for monitoring and evaluation of RA were lacking. They felt that RA at AHS level was not transparent, nor were AHSs as accountable as they should be to senior NSW Health managers. AHS managers also noted that the Department's emphasis on efficiency limited their ability to allocate resources equitably, and the lack of coordination (at that time) between the various service providers limited the equity of allocation of funds and services at the AHS level.

3.8 A case study of a consultation process in the formulation of policy

As Kirigia explained, it is clear from statements issued by NSW Health that it recognised that geographical inequity in healthcare funding existed in NSW and that it had an obligation to reduce this inequity and to allocate funding in order to do this (295). While Kirigia's study was about constraints on the implementation of policy and on the success or otherwise of policy implementation, in 2007 Hyde published a case report on the process of consultation with senior

NSW Health managers (AHS Chief Executive Officers (CEOs) and some Head Office officials, but no politicians), which led to the production of NSW Health's Equity Statement in 2004 (296). The discussion among CEOs which Hyde reported concerned the formation of a policy not about how RA decisions are made, but about how they should be made in order to achieve equity.

Although evidence from case studies is traditionally assigned a low rank in the hierarchy of research methods (321), as Yin pointed out, they have an important role in answering "how" and "why" questions (322) and are especially informative when, as in this case, generalisation is difficult due to the variability in the circumstances of individual cases of policy decision-making and when illustration is more important than generalisation. Hyde's (2007) approach was simple exposition, with little attempt at interpretation, and no statement of a philosophical standpoint. Although the author didn't discuss what he meant by the term "equity" (i.e. horizontal equity or vertical equity – see section 7.5), the participants in working groups whose views he summarised placed considerable importance on vertical equity: that is, supplying extra healthcare to the disadvantaged, such as Aboriginals and people living in remote areas, recognising that the inverse care law (1) operated in NSW and especially in remote areas (296).

Participants in Hyde's study agreed that access to publicly funded and supplied healthcare should be based on need, not on demand, and eight of the 12 participants agreed that equity of health outcomes was the most important aspect of equity to be achieved. All of the participants recognised that NSW Health had a responsibility to ensure equity of RA between geographic regions of the State, and equity of needs-based access to healthcare services, and that a policy should be formulated to achieve this (296). The participants also felt that NSW Health should, as a matter of policy, act as an equity advocate across government in NSW and should form links with other departments and other service providers, recognising the links between social participation and control and health outcomes (296). As Kirigia's investigation found, however, there's many a slip between formulation of a policy and its implementation.

The above sections describe the process of healthcare RA decision-making from the perspective of Australian health bureaucrats, the efforts made in an Australian jurisdiction to achieve equity in decision-making, and the success or otherwise of those efforts. The next section discusses published data on international views of the process of RA decision-making and the influence of ethical considerations on it.

3.9 The views of international decision-makers on how resource allocation decisions are made

In a 2012 literature review, Guindo et al. from the University of Montreal (264) searched the medical literature (via Medline, Embase and a bibliography search of relevant articles) for articles in English, French or German which discussed criteria for healthcare RA decision-making, published between 2000 and 2010. These included articles based on primary data (interviews, focus groups or surveys of decision-makers), review articles and articles discussing multicriteria tools, but not case reports and discussions of single criteria. They did not search the political or administrative literature, which may well contain articles with a different perspective from those which they found, and their inclusion of articles discussing RA at micro and meso as well as macro levels limited the applicability of their findings in the current investigation, which was principally concerned with macro level RA. Furthermore, their inclusion of some articles proposing a set of criteria may have biased their overall findings towards some criterion which *should* be used, rather than towards those which *are* used, given the fact that they used the number of studies in which a criterion was mentioned as a proxy for its importance. In Guindo et al. (2012), the views expressed in the articles proposing a set of criteria are not separated from those of articles which describe criteria actually used.

In the 40 articles from the published literature which fitted their criteria, the most frequently mentioned criteria for guiding RA decision-making were, in descending order: equity, fairness and justice (32/40); efficacy or effectiveness (29/40); stakeholder interests and pressures (28/40); cost-effectiveness (23/40); strength of evidence (20/40); safety (19/40); mission of the health system (19/40) and organisational requirements and capacity (17/40). Among the fairness/ethics criteria, the most commonly appearing terms were: equity, fairness and justice (32/40); access (17/40); ethics and moral aspects (14/40); vulnerable and needy populations (11/40); solidarity (8/40; population priorities 5/40 and utility (3/40). The authors commented that normative criteria dominated over feasibility criteria such as stakeholder pressures and organisational needs and capacities, and that this may reflect the fact that they sampled the medical rather than the administrative literature (264).

The authors commented that in view of the fact that "equity is difficult to operationalize … in a pragmatic manner," fairness should be "included systematically … in the decision process" and that more value should be given systematically to interventions that target vulnerable populations such as children, the elderly and people living in remote locations (264); that is, there should be a systematic commitment to vertical equity (see section 7.6) in all RA decisions. They also noted that stakeholder interests and pressures was the third most commonly mentioned criterion; stakeholders

may include the public (i.e. public opinion, discussed in section 3.15) and healthcare providers. Pressure from this latter group may, as Sidney Sax pointed out in 1984 in *A Strife of Interests*, be a force for instigating change or for inhibiting change, and may limit the feasibility of any decisions made at political or administrative level (304). Safety was the sixth most frequently-mentioned criterion in Guindo et al.'s study (264). This may be reflected in governments' and administrators' perceptions that low-volume facilities are associated with increased risks and worse health outcomes for any given illness (323-326).

3.10 The meta-structure of healthcare resource allocation decision-making

The literature described above discusses a theoretical model to describe the decision-making process (283), constraints on decision-making (265) and the role of individual criteria in decision-making (264, 265, 296). Ham and Coulter's (2001) opinion piece/narrative review argues for a more transparent and accountable process of healthcare RA decision-making, and for more involvement of the public in that process (162). The authors' aim was to summarise the work done in several countries (Denmark, Finland, Norway, Sweden, the Netherlands, the UK and New Zealand) in developing an explicit and transparent approach to healthcare RA. The authors' secondary aim was to advocate a greater role for public participation in decision-making about what resources should be available, and to whom. Their argument is based on a selection of the literature on the subject prior to 2001, and they present the opposing arguments on the subject of implicit versus explicit decision-making, together with their own coherent argument for a combination of the two methods.

Ham and Coulter noted that New Zealand and the Netherlands (as of 2001) avoided limiting the services provided (unlike the healthcare planners of Oregon in the late 1980s, who discovered that economic methods of comparing costs and outcomes of medical treatments were insufficiently developed to be relied upon for decision-making about RA). Instead, New Zealand and the Netherlands used evidence-based guidelines to target services to those most likely to benefit. One purpose of those guidelines was to increase the transparency of the decision-making process. As the authors pointed out, however, one role of guidelines is to decentralise decision-making, and reduce the odium felt especially by politicians when unpopular choices (e.g. about hospital closures) are necessary. Morone, writing in the *University of Pennsylvania Law Review*, described the American way of rationing as "to decentralize (in political terms, hide) the choices; the result is rationing through an accumulation of narrow public policies, private decisions and luck" (327).

Ham and Coulter pointed out that "one of the reasons political leaders have been reluctant to engage in explicit rationing at a macro level in the past is that in determining priorities they are also accepting responsibility for what may be unpopular choices" and "a common thread in both North American and European experience is the need to show that the way in which priorities are set is fair and reasonable even if agreement on the outcome is not possible" (162). This, of course, refers to Daniels and Sabin's widely-quoted paper outlining the principles of A4R and its consequent wide acceptance in the European literature as a starting point for progress in process-based decision-making (249, 250, 252, 255).

Ham and Coulter expressed the view that progress in decision-making cannot be made simply by improving the quality of evidence available on which to base decisions, nor can it be made only by "muddling through elegantly" (161) (by strengthening the institutional mechanisms which facilitate debate and compromise between the different interests involved, in the absence of full information about the question to be decided, on the grounds that complete explicitness about decision-making is neither politically possible nor desirable (161)). Instead, they argued that both the technical approach (the extent and quality of information available, on which to base decisions) and the techniques of decision-making must be improved. This is a motherhood statement to some extent, but the authors provide some detail about how the improvement in process might proceed by combining implicit (e.g. guidelines) and explicit rationing processes. Further, they advocated greater reliance on public consultation (see below) in healthcare RA: "the rationale for encouraging democratic deliberation is that choices in healthcare involve moral issues that should be neither hidden nor fudged" (162). One problem of public participation, however, is that there are many "publics" (312). Who should be consulted and what weight should be given to the opinion of each group? That weighting is crucial and itself requires a value judgement which must be explicit and transparent.

As noted earlier, the use of economic evidence and analysis in governments' healthcare decision-making has been strongly advocated in Australia (223, 228, 229), the UK (230), (231) and elsewhere (232, 233). However, its usefulness in practice is widely questioned (302, 303), so we might ask: how useful has economic evaluation of treatments and programs proved to be?

3.11 What is the role of economic evaluation in resource allocation decision-making in Australia?

Ross (1995) (236) reported the results of semi-structured interviews with 34 senior healthcare decision-makers from the Australian Department of Health, Housing and Community Services and

the NSW Health Department (head office and AHS levels). The aim of her research was to identify the ways in which economic evaluation was used in practical RA decision-making and to identify barriers to its greater use. The results of the interviews were reported in numerical terms (the proportion of respondents who gave each summarised response) rather than in the individuals' own words.

While the great majority understood the principles of economic evaluation, only 38% had used it or were currently using it to inform their decision-making. Half of the remainder were planning to use it in future decision-making. The principal barriers to its use, according to Ross' interviewees, were political factors, the nature of existing policies, administrative feasibility, considerations of equity, the availability of relevant information and pressures of public or pressure group opinion (236).

In this small preliminary study, Ross did not enlarge on which class of decision-maker (federal or State, central or local, administrator or policy adviser) gave which sort of response to questions. Moreover, she did not explain the degree to which her sample of participants was representative of the larger group of decision-makers in Australia. Her findings however, were consistent with those of Baghbanian et al. in 2011 (235), who noted that in the literature to that date "the bulk of evidence concerning local policy decision-making shows very limited or no use of economic evaluations." In Baghbanian et al.'s study, 379 healthcare administrators from the Australian and NSW Departments of Health and an unspecified number of others from non-government or private organisations with responsibility for RA decision-making were invited by email to respond to an online questionnaire; 91 (24%) responded. Only 56% of respondents reported that they had used economic evaluation; federal bureaucrats and senior personnel were more likely to understand its value. Respondents noted that ethical considerations, policy guidelines, financial and time limitations and the availability and relevance of evidence limited their use of economic evaluation (235).

Baghbanian et al. (2011) noted that their sample size was not large enough to generalise to the whole population (of healthcare decision-makers) or to draw firm conclusions about the use of economic evaluation by different classes of decision-maker. They noted, however, that since 1993, economic analysis has been an essential part of the assessment of medicines for subsidy under the Australian PBS (235). Their structured questionnaire constrained the range of responses available to participants and the authors' ability to discover the exact role of their knowledge, experience and circumstances in determining participants' response. Self-selection may have affected the range of individuals who responded (perhaps more junior personnel and those with more available time being more likely to respond).

Galani and Rutten's (2008) systematic review (308) examined 55 original studies from a variety of countries (mostly the US and UK, but also Canada, the Netherlands and other countries, including Australia) of the extent to which economic evaluation was used in health policy decision-making. Of those 55 reports, only 21 concerned macro-allocation as defined in this thesis, the rest being meso or micro-allocation. Thirty-six per cent of studies at macro and meso level reported that the use of economic evaluation was increasing. The findings of this review are difficult to interpret for an Australian context, given that the country contributing the largest number of studies (the US) has laws expressly forbidding the use of CUA in healthcare priority settings, while economic analysis is an integral part of the formation of policy advice produced by the UK's NICE. Galani and Rutten made little attempt to analyse their findings by level (i.e. macro, meso or micro) of decision-making: this means that it is even more difficult to apply them to the present macro-level study. Their findings on limitations to the use of economic evaluation are relevant, however: they found research-related barriers (timely availability of recent research data_, credibility (i.e. not pharmaceutical company-sponsored), poor methodology (non-transparent methodology, not peer-reviewed) as well as decision-maker barriers (inexperience with economic data, inflexible health budgets, non-acceptance of economic information) which may be relevant to the Australian context, as Ross and Baghbanian have shown (235, 236).

3.12 The use of economic evaluation in allocating healthcare resources to children

Several authors have criticised the use of QALYs in healthcare priority-setting which affects children, on the grounds that while several weighting systems have been proposed for childhood illness, there is no standard system. Systems designed for adults do not take into account the child's developmental stage, and there is no widely accepted system for use in children younger than five years (224, 328). In very young children, a parent is used to answer the questions in the utility analysis as a proxy for the child; this brings the problems that first, the utility of the parent may affect their perception of the utility of the child, and second, the parent can only recount what he or she sees, not what the child actually feels. Because QALY weighting systems for children are necessarily different from those used for adults, child QALYs and adult QALYs are not comparable (224, 328).

In response to the (ongoing) enthusiasm for using QALYs to assess health state and healthcare programs in children (329, 330), Keren et al. (2004) published a narrative review of the differences between adults and children which affect the design, interpretation and use of economic evaluation of healthcare programs that affect children (309). These include biological and developmental

issues, dependence on others, the fact that significant illness outcomes may only be experienced after some years, different opportunities in children to experience life, different capabilities, the different socio-economic status of children, and their disenfranchisement from political or legal redress (309). This was essentially an expert opinion paper, based on the experience of its authors; it did not make a case against the use of CUA in children, but discussed the practicalities of using adult proxies to estimate the utility of a child, and suggested a schedule of questions to be asked in any economic analysis which affects children, especially those in which children's utility is compared with that of adults.

3.13 The views of the Australian public on economic evaluation in healthcare resource allocation

The use of CUA to assign priorities to healthcare programs is based on the validity of QALYs as indices of individuals' health gains and on the presumption that the society as a whole wishes to use limited resources in a way that maximises the sum of individual health gains, regardless of who (child or adult; deserving or undeserving) receives each QALY gained (313). In two papers published in 1995, Nord et al. assessed Australian public opinion on the latter point (distributive neutrality). The authors distributed a questionnaire at random through suburban and rural areas with a range of socio-economic profiles. Respondents were asked to assume that financial and donor organ resources were limited and were asked to choose one of three alternatives in each of six scenarios. The response rate was 28%. Respondents were unwilling to favour younger patients against the very old and gave the same priority to all patients, regardless of age, both to medical care that improves the quality of life and to that which saves life. That is, respondents rejected the principle of maximisation of health benefits (in terms of QALYs gained) when it would lead to loss of equity (313). The authors concluded that "there is clearly a benefit from the knowledge that society is 'just' and that its rules of social justice correspond with personal values."

Respondents favoured organ donation to children rather than to newborns (on the grounds of presumed greater likelihood of a successful outcome) although donation to a newborn would deliver more QALYs. Among this group of the Australian population, the principle of favouring those most likely to benefit took precedence over that of maximisation of aggregate QALYs. Sixty per cent of respondents felt that non-smokers should be given priority over smokers; that is, they felt that those whose actions contributed to their health state should be given a lower priority than others. This may have some implications for the allocation of healthcare resources to those who choose to live far from population centres and thus from healthcare facilities.

In a second stage of Nord et al.'s study (311), 60% of respondents to the first survey were interviewed about the importance of costs in allocating healthcare resources. Eighty-one per cent rejected the principle that illnesses requiring high-cost treatments should receive lower priority. This has implications for allocation of healthcare resources to those in remote areas, where delivery of care is far more expensive than in the city or large town. Respondents rejected favouring employed people, whose tax contribution, if treatment led to their survival, would allow more people to be treated. That is, this group of respondents favoured equitable treatment of individuals over maximisation of aggregate health gains. The authors pointed out that the self-selected respondents in this second stage had higher educational attainment and were more likely to have private health insurance than the Australian population as a whole, so that their views may not have been representative of all Australians (311).

Investigating a similar point, McKie and Richardson (2011) distributed questionnaires to 1500 suburban Australian households in a range of socio-economic areas to discover the views of the public on the fairness of considering indirect benefits in healthcare priority settings (262). The response rate was 28%. Respondents rejected preferential allocation of resources to those who were more connected to the society and to those whose taxation contribution could benefit others if they survived. Indeed, 87% felt that only medical need should determine whether an individual should receive medical care. Even when the opportunity costs (in terms of ability to supply treatment to other people) of failing to give priority to high taxpayers were pointed out, the majority of respondents felt that individual need rather than potential indirect financial benefits should determine RA. Although the authors' sample was self-selected in terms of response, and was unrepresentative of the Australian population in its age and education profile, when the authors corrected for these factors, the findings were unchanged.

As well as advocating that the views of the public on particular aspects of the decision-making process be canvassed, several authors (including Ham and Coulter, as described earlier in this chapter (162)) have proposed that the views of the public should be solicited in individual RA decisions. This is discussed in the following section.

3.14 Public participation in healthcare resource allocation decision-making

Several reviews, opinion and advocacy articles as well as original research articles have addressed the issue of the role of public opinion in determining priorities for the allocation of healthcare resources (311-313, 331-335). Mitton et al. published a critical review of the literature on the subject

in 2009, in particular examining the questions of whose opinion to solicit and how to recruit members of the public, what degree of public participation delivers the best outcome, what methods of consultation are most effective, and how the results of public consultation are integrated into the decision-making process (333). Their study did not address the arguments for and against consulting the public, though other authors have done so (331). Mitton et al. found 175 empirical reports of the use of public consultation, mostly of healthcare allocation decision-making, but included a few reports from the urban, environmental and transport planning literature. A wide range of consultation methods was found, from surveys and questionnaires to face-to-face interviews and focus groups. Similarly, they found a range of levels and duration of participation of the public in the decision-making process.

Allowing for the fact that original authors reporting a novel consultation process are likely to report it as having been "successful" or "effective", Mitton and co-authors found that face-to-face interviews (rather than methods with less personal involvement) repeated rather than one-off contact between interviewer(s) and participants, and two-way interaction between decision-makers and consulted members of the public was associated with these reports judging public consultations as "successful" (333). Two thirds of the papers surveyed used purposive sampling of participants (rather than random sampling or self-selection), and more than half of these intentionally sampled disadvantaged groups (such as Aboriginal persons, children or the poor), on the grounds that sampling a general population may not identify the particular needs of these groups (333). Given the exploratory nature of this literature review, Mitton et al. were unable to conclude that one or other method of sampling or mode of public consultation was preferable to or more effective than the others. Instead, they took the findings of the studied papers at face value, using them as a basis for guiding future research.

In another exploratory study, Mooney et al. (1995) investigated the views of the Australian public on RA. The "public" whose views they solicited by means of a questionnaire, however, was rather a special one; they were attendees at an Australian conference for healthcare decision-makers, whose opinions were sought "in the belief that this group may indirectly reflect the preferences of the community" (334). This assumption may be false, and the authors made no attempt to verify or refute it, so it is unclear how well participants' views represent those of the general Australian community. In addition to this issue, the true response rate of completion of questionnaires was unknown, but the authors estimated it at 40–50% of those approached (334).

The authors found that respondents were willing to allocate a higher proportion of health gains to those with a greater degree of need, regardless of the number of patients involved, but were not

willing to discriminate on the grounds of age, sex or socio-economic status (334). The findings of this early attempt to sample the views of the Australian public should be treated with caution, given the role of the participants as decision-makers as well as members of the public, and also given that, as public servants or health professionals, the educational, geographic, linguistic, age and socio-economic profile of the sample is likely to have been very different from that of the general population.

3.15 Should the views of the public be taken into account?

Wiseman et al. (2003) examined the issue of whether the Australian public believes that "the general public has a legitimate role to play in informing priority setting in healthcare" (331). The authors invited 373 English speakers over the age of 15 in two inner-Sydney medical clinics to complete an interviewer-assisted survey about whether the preferences of the general public should be used to inform various types of healthcare RA decision. Almost 80% of respondents felt that the preferences of the public should be taken into account in setting priorities for healthcare programs (i.e. macro-allocation) and population groups, but slightly fewer (74%) believed that citizen preferences should be taken into account in priority-setting among medical interventions. Ninety-seven per cent felt that more than one group should be consulted in decision-making (i.e. not just patients and their families or single at-risk or disadvantaged groups). Interestingly, only 3% of the sample felt that the views of politicians should have the most influence in allocating healthcare resources between programs, population groups or medical interventions (331), in striking contrast with what happens in actual decision-making (see sections 3.7 and 6.1).

Wiseman et al.'s findings may have been influenced by the nature of their convenience sample; only English speakers and those who felt well enough to respond were sampled. Participants were approached in inner-Sydney clinics, and so were likely to be preponderantly from an inner-urban population, whose views may not reflect those of the general population. Females were over-represented (68%), and respondents had higher educational attainment and were more likely to have private health insurance than the general population (331). The fact that the survey was interviewer-assisted may also have influenced the views that participants were willing to express.

3.16 How should the community be consulted? An Australian example of public consultation in priority-setting

As seen above, the methodology of the consultation process may profoundly affect its findings. In 1998, Alexander and Hicks (312) reported on a consultation process to inform the Adelaide Women's and Children's Hospital's decision-making about the services it should provide. The first part of their

paper is a narrative review of some aspects of decision-making about healthcare RA in Australia, especially in NSW and South Australia. The authors addressed the role of public consultation and the importance of assessing the needs of sub-populations rather than looking at whole-population averages of need. On the latter point, they asserted that:

> a merely epidemiological approach (to needs assessment) also runs some risk of summarising and simplifying to the point where sub-populations are averaged out of sight … 'The Public' is made up of many publics whose experience is distributed widely around the average. (312)

Alexander and Hicks (1998) pointed out the inadequacy of public opinion surveys for elucidating the actual views of members of the public. They noted that the questions asked and the language in which they are expressed "tend to suppress variability because they presume that individuals chosen by randomisation and confronted with a standardised questionnaire produce homogeneous answers which can be rolled together to produce a population average" (312). Using a survey to inform healthcare RA decisions, they wrote, "presumes triggers for human wants and satisfactions"(312) much simpler than those found when motivations of individuals are investigated more closely, and offers no means of accounting for the effect of the beliefs, knowledge, experience and circumstances of individuals on their responses to survey questions.

In line with the arguments expressed above, the Adelaide Women's and Children's Hospital conducted five workshops in 1995-7 to explore the views of the public on the services which it should offer in a financially constrained environment. These workshops and their results were reported by Alexander and Hicks (1998) (312). The participants in these groups were rural and urban community members (selected to represent the range of different parties with interest in women's and children's health); rural and urban primary healthcare workers, and hospital staff. Each group was given a theoretical budget and a set of competing healthcare programs with information on their costs and benefits. They were asked to develop criteria according to which the order of priorities should be allocated to these programs. The approach of the focus group organisers, rather than being an oppositional one ("should this program or that program be chosen?"'), was to ascertain a "vector sum of values" of the group, with regard to equity, expenditure in the face of funding limitation, freedom of choice and comprehensiveness of care. This approach aimed more to elicit the views of participants on the sort of world they would want to inhabit than to elicit opinions on the relative merits of individual healthcare programs. Knowledge of the participants' world views would then inform decision-making (312).

There was considerable agreement between groups on the order of priorities for these principles (e.g. programs aimed at early diagnosis and treatment consistently rated more highly than curative

or life-prolonging programs) (312). It could be argued though, that the opinions of groups selected for their expertise or interest in health and healthcare may not represent those held in the wider community and the process may be less successful in a society less homogeneous (in terms of education, socio-economic status, ethnicity and political and religious belief) than that of South Australia in the 1990s. The outcome will be critically dependent on the selection of participants and on the forcefulness with which each subgroup expresses its views, which in turn will determine its influence on others in its focus group. Some disadvantaged participants, such as rural adolescents, may have less influence on outcomes than others who might be more vocal or charismatic.

The principles adopted in selection of participants may reflect the attitudes and biases of the study organisers and possibly of the decision-makers, and the findings of such opinion-seeking studies may therefore merely be what the decision-makers wanted them to be. Although this report concerned meso-level (i.e. hospital program) decision-making, the consultation methods which it reports are relevant to, and feasible for, macro-level (i.e. government department) decision-making.

In Alexander and Hicks' (1998) study, there was no discussion of the relative merits of ethical principles such as rights or justice. However, senior hospital staff ranked equity of access above the concept of "most benefit to the greatest number," and the concept of need (access to services for those most at risk) was mentioned, though the participants ranked it lower than principles such as maintaining quality of life and research and health promotion.

3.18 Summary

The aim of this chapter was to examine the existing published and grey literature on decision-making about the role which ethical principles play in the making of healthcare RA decisions which affect rural children, with emphasis on Australian experience, the views of Australian decision-makers and of the Australian public. The chapter described theoretical models of decision-making, including an Australian model of healthcare resource decision-making based on empirical observations (283) and descriptions of RA models from countries with similar health systems (162). Government documents intended to give ethical guidance to priority setting in healthcare were described, together with a case report of the process of development of one such document (296) and an examination of the degree to which one such RA policy has been successful (265). The roles of economic evaluation and public consultation both in Australia and elsewhere were described, together with the attitudes of the Australian public to both processes.

The weaknesses of the literature in this area to date are first, that the exact issue of the role ethical principles play in the making of healthcare resource allocation decisions which affect rural children

has not been addressed at all. The candidate found no literature (published or otherwise) on the principles which govern the allocation of healthcare resources to children. The principles of efficiency and value for money, as well as the principle of equity in priority-setting about policies which affect rural persons are mentioned in government documents, and the limited degree to which they are followed was explored in this chapter. The issue of healthcare allocation to rural children, given their state of dependence on others and their worse health outcomes than urban children, has not been explored in the published or grey literature. A second weakness is the failure of many articles in the area to address a precisely stated question or to discuss the issues of possible selection bias (in the case of surveys) or of data saturation (in the case of qualitative studies). A third weakness is the low response rate (24–28%) of published surveys (283, 313, 335). This low response rate, together with the possibility of bias due to self-selection among responders reduces the credibility of the findings of those surveys.

In view of the lack of discussion of this topic in the published literature, the candidate undertook an investigation of the way in which government officials are guided by ethical principles in their decision-making about RA and analysed data from a survey of the experiences of families in accessing healthcare for their children when healthcare is allocated according to those principles. The methods employed are described in the following chapter.

Chapter 4: Methods

This chapter describes the mixed-methods approach used to answer the research questions which were posed in Section 1.2. Those questions are as follows:

1. What healthcare resources are currently available for children in rural and remote areas in Australia?
2. How do parents experience the provision of healthcare resources for their children and the consequences for their child and family of that pattern of resource provision?
3. How are healthcare resources allocated to rural children, and what factors are considered?
4. What ethical framework underpins the allocation of healthcare resources for children now?
5. What ethical framework could guide healthcare resource allocation for rural children in a way that best fits their needs and those of their families and government health officials?

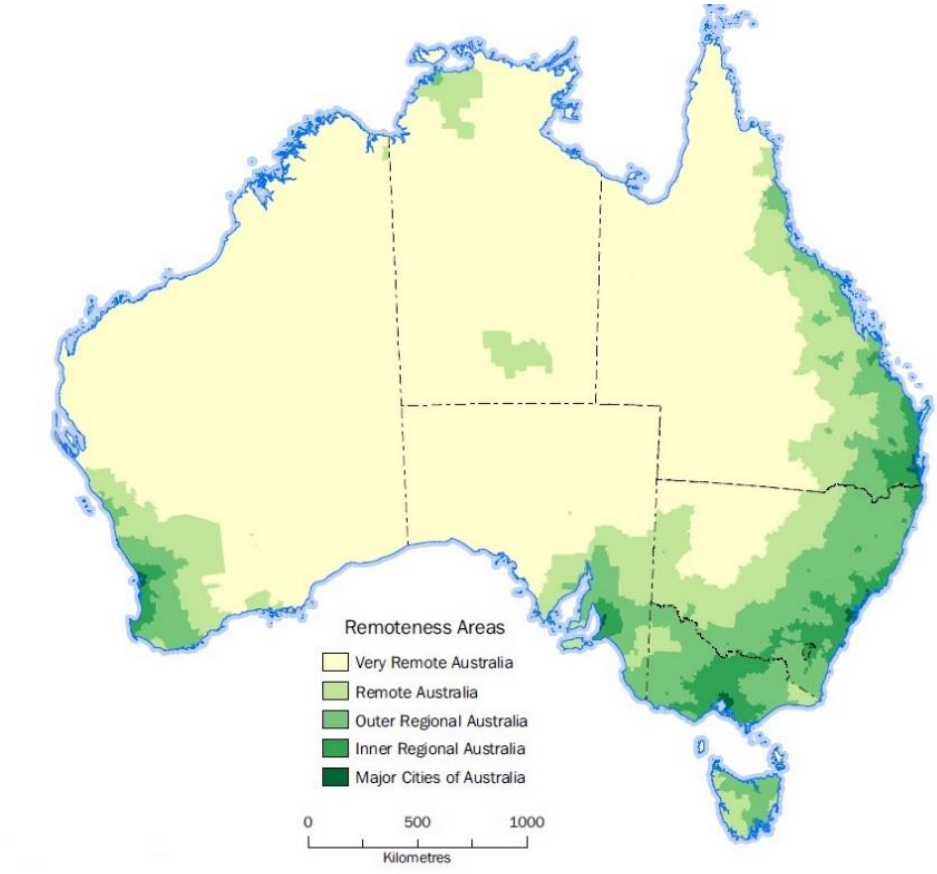
In answer to question 1, Section 4.3 describes how the locations of healthcare resources for children in rural Australia were ascertained , using Western NSW as an example. The results of that investigation are described in chapter 5. To address question 2, qualitative interviews were conducted with parents who used rural health services for their children. The recruitment of parents for interview and the role of the data in answering question 2 are discussed in sections 4.4–4.6. Further information on the healthcare experiences of rural parents was obtained by quantitative analysis of survey responses to NSW Health Child Patient Health Surveys conducted between 2011 and 2014. This survey and the process of analysis are described in section 4.7; the results are set out in Chapter 5. To address questions 3 and 4, qualitative interviews were conducted with officials of the Australian and NSW Health Departments and with their healthcare advisers. The interview process, recruitment of participants and the analysis of data from the interviews are discussed in sections 4.9–4.15; the results are shown in Chapter 6.

Chapter 1 describes the disadvantage of rural children in healthcare outcomes compared with their urban counterparts, and reviewed the evidence concerning the role which differences in access to healthcare plays in perpetuating these rural–urban differences. That chapter also explains why children may be especially vulnerable to disadvantage in access to healthcare resources. The next section explains why NSW, and in particular Western NSW, was chosen as an example of RA in Australia as a whole.

4.1 NSW as a site for study

Much of the Australian population lives in large state capital cities or in regional cities such as Newcastle, Townsville or Geelong, but some Australians live in sparsely populated areas, far from major centres. The ABS classifies all of the continent and islands of Australia into regions of levels of remoteness: Major Cities, Inner Regional, Outer Regional, Remote, and Very Remote (see Appendix 1 for details). Figure 3 shows areas of Australia classified according to their level of remoteness.

FIGURE 3 REMOTENESS AREAS OF AUSTRALIA, 2011

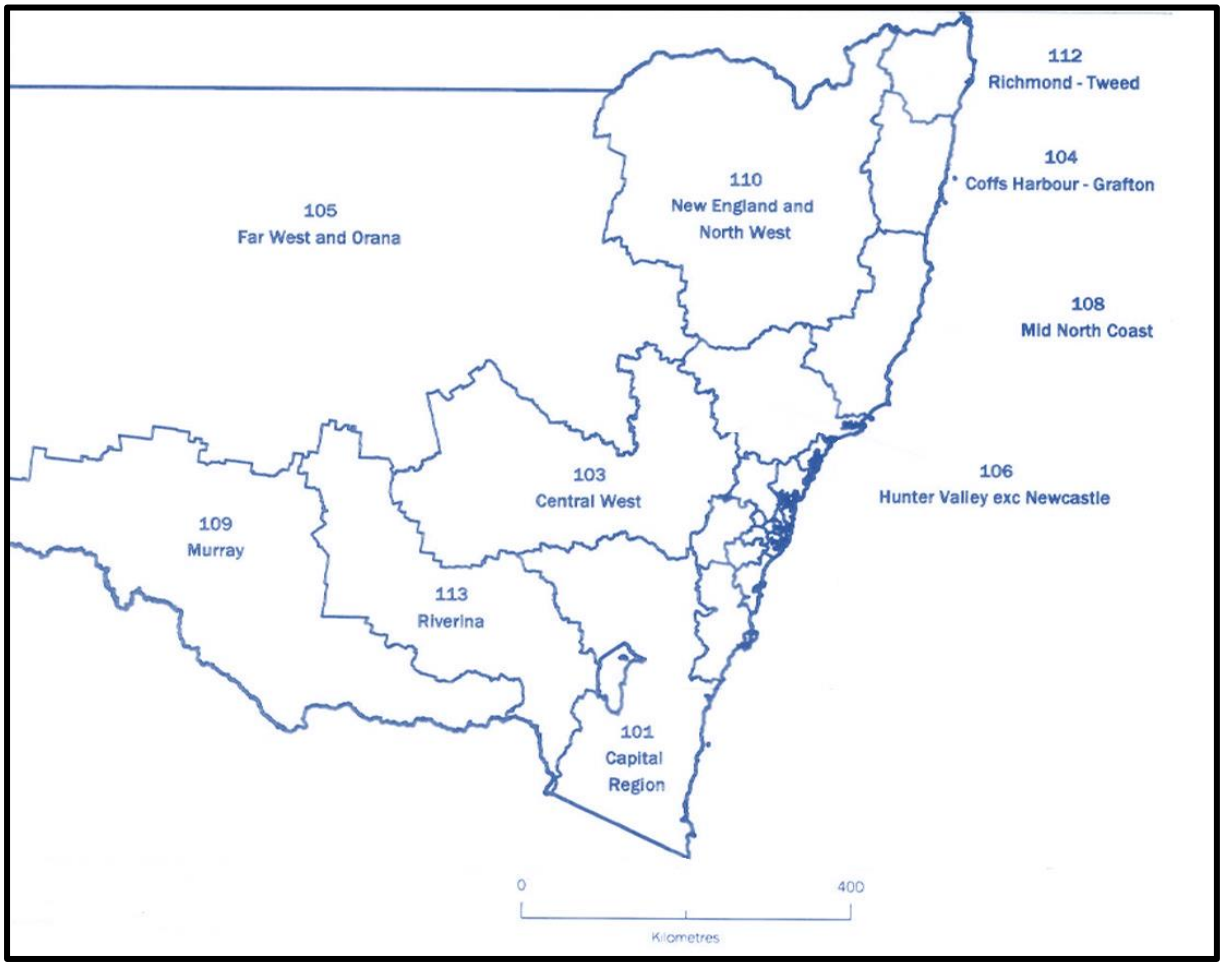


Adapted from ABS (2013) (336)

Figure 3 also shows that the proportion of each state's area which is remote or very remote varies, but that NSW has areas of all levels of remoteness (Appendix 1). Although initially, Victoria was considered as the appropriate area for this study because of the proximity of Victorian healthcare RA decision-makers to the University of Melbourne where this study is based. Initial approaches were made to arrange interviews with officials of the Victorian Department of Health. However, it became apparent that the effect of remoteness on the distribution of healthcare resources was less marked

in Victoria (which has only very small Remote regions and no Very Remote regions) than in other states. Western NSW, on the other hand, (see Figure 4) contains areas of all levels of remoteness apart from Major Cities (Appendix 1), so Western NSW appeared to be a suitable location for a study of RA to rural and remotely located children. The practicalities of performing a study in the time available to a PhD candidate made it necessary to study a representative area of Australia rather than the entire country. Published records of Health Department policies, including resource distribution policies, and of patient experience surveys were available for NSW, but less so for other states. For these reasons, the candidate elected to study healthcare RA by the Federal Department of Health and Ageing, by the Head Office of NSW Health and by the Western NSW and Far West LHDs of NSW Health. Appendix 3 shows the percentages of the Australian child population who reside in areas of each level of remoteness.

FIGURE 4 MAP OF NEW SOUTH WALES, SHOWING STATISTICAL AREAS SA4



Map adapted from ABS (2011) (337)

As noted in sections 1.6 and 1.8, healthcare contribute to the health outcomes of children, so children require access to both primary care, such as that provided by GPs, Aboriginal health centres

or nurse-led clinics, and more complex care such as that provided by allied health practitioners or paediatricians. Complex healthcare for children in NSW is centralised (located in cities and larger regional towns), as it is in the other Australian states. NSW has good data collection and record-keeping within the Health Department. A PhD thesis (265) in 2009 addressed the issue of the extent to which the NSW funding formula of that time achieved the equity which the Health Ministry professed to deliver. It came to the conclusion that equity was achieved to a very limited extent (i.e. that other considerations such as political ones, were more important (265)). This means that there are numerical data on the subject of RA equity. However, there appears to be little real exploration in the published or unpublished literature of alternative ethical principles which inform healthcare RA, and no exploration of the use of ethical principles in practice to guide healthcare RA to children.

4.2 What are the gaps in the literature?

Chapter 1 identified a problem which needs remedial action. That is, children in rural areas have less favourable health outcomes in terms of mortality and morbidity than urban children for a range of childhood illnesses, and not all of those differences in health outcome can be explained by rural–urban differences in disease epidemiology. Chapter 2 gives a theoretical overview of healthcare rationing, its process and the influences on it. Chapter 3 contains a review of the discoverable literature on healthcare rationing in practice, with emphasis on Australian studies. It shows the scarcity of empirical information on how allocation decisions are made, especially in Australia, and on the role of ethical principles in healthcare RA decision-making, and the lack of empirical data on how the interests of children (and especially rural children) are taken into account when RA decisions are made. To accomplish the aims of this thesis (set out in section 1.2), given these gaps in the literature, a research plan with the following three components was formed:

- to identify the geographic location of healthcare resources for rural children in an Australian state which has areas of levels of remoteness which vary from Major Cities to Very Remote;
- to understand the experiences of rural families in gaining access to healthcare for their children when resources are geographically located in this way; and
- to understand the considerations (and in particular, the ethical considerations) which underlie the allocation of healthcare resources which contribute to their distribution and to rural families' experiences.

To address the first issue, publicly available information on the geographical location in Western NSW of a range of healthcare resource which are important for the care of children were obtained and their presence or absence in rural populations of various sizes was established. To study the second issue, the candidate interviewed parents of rural children and analysed unpublished data

from the NSW Health Child Population Health Survey. In order to identify the ethical assumptions which underlie healthcare resource decision-making, the candidate interviewed government officials whose role involved making healthcare RA decisions, or advising the executive on such decisions. The following sections discuss the levels of government at which such allocation decisions are taken; the region of Australia studied in this research; the recruitment of participants; and the interview and data analysis processes.

4.3 Distribution of healthcare resources for children in rural NSW

Coordination of paediatric healthcare in NSW is guided by a 2002 policy statement from NSW Health(338) . This document sets out the principles which the Department intended should guide the planning of healthcare services for children in NSW. The aspects of healthcare which were to be considered in these principles were safety, consumer participation, effectiveness, access, appropriateness and efficiency. These aspects were to be accommodated by organising paediatric healthcare in the state into three networks, each based on a tertiary paediatric hospital. These networks were:

- Western Child Health Network, linked to Children's Hospital, Westmead and including Western NSW and Far West LHDs, as well as western, south-western and northern Sydney;
- Southern Child Health Network, linked to Sydney Children's Hospital and including the Southern NSW, Illawarra Shoalhaven and Murrumbidgee LHDs, the Australian Capital Territory and Southern and South East Sydney; and
- Hunter and Northern Child Health Network, linked to John Hunter Children's Hospital in Newcastle, and including the Mid North Coast, Northern NSW and Hunter New England LHDs.

Each network includes a rural component, an urban component and a tertiary children's hospital. Tertiary paediatric inpatient services such as paediatric cardiology or paediatric nephrology are available in the three paediatric hospitals, while paediatric subspecialty outpatient services are provided intermittently by visiting specialists in some larger centres such as Dubbo, Mudgee and Bathurst.

According to this 2002 document, the principles which should guide paediatric healthcare service provision in the state are:

- maintaining the child in the family environment and engaging GP and outpatient services in reducing the need for, and duration of, hospital admission;
- prevention, including early detection, health education and health promotion;

- education and support of parenting skills;
- integrated care within and between the networks and the use of common guidelines and protocols;
- involvement of local service providers in planning services and decentralisation of care wherever possible;
- centralisation of subspecialty services but improvement of access to these with the use of subspecialty outpatient services at regional hospitals;
- increasing the use of ambulatory care services; and
- improving communication between centrally-located subspecialists and local (including rural) primary healthcare providers.

The degree to which these goals and the goals of networking of paediatric care are achieved from the family's perspective, is assessed in NSW Health by means of regular Statewide Population Health Surveys, of which summaries are published online by the NSW Health Bureau of Health Information (339). Data from the last four of these surveys to examine patient experience (the 2011–14 surveys) was analysed as part of the present investigation (see sections 4.5–4.8).

While the 2002 policy statement sets out the principles which should guide the allocation and networking of healthcare resources relevant to children, the ease with which rural families can gain access to services depends at least in part on where those services are located. To examine the issue of location of healthcare resources relevant to rural children, the example of Western NSW (ABS SA4 areas Central West and Far West and Orana) was used (Figure 4).

In order to connect information available from disparate sources such as the ABS QuickStats data from the 2016 census(340) and the National Health Services Directory (341), the candidate examined the resources available at State Suburb (SSC) level (for definition of State Suburb, see the Glossary). ABS QuickStats gave information on the total population and the child population of individual SSCs, and the National Health Services Directory provided the map coordinates of all health services in Western NSW relevant to the healthcare of children. While the provision of many health-related services in Western NSW affects the health and the healthcare of rural children (e.g. dental services, dermatology services, child and adolescent psychology, rehabilitation services, palliative care, dietetics and wheelchair rental services), only a selection of commonly used child healthcare services were examined in this research.

The coordinates were used to map the services on a base map of Western NSW, using a Geographical Information Systems program called QGIS (342). Using information from Quickstats, those coordinates could then be mapped to individual SSCs. SSCs (rather than some other

geographical sub-unit) were chosen because information on their location, population size, child population size and health service content was publicly available, whereas all of that information was not readily available for other geographical sub-units, such as SA2 (see Appendix 1).

4.4 The role of interviews with parents

Rural children and their families are an important group of people who are affected by the way in which healthcare resources are currently distributed (described in sections 4.3 and 5.1). The effects on that group, of the current methods of healthcare RA, can be examined in several ways:

- by comparing the health outcomes of rural children with those of urban children, both with respect to mortality and with respect to indicators of morbidity, taking into account differences in disease epidemiology (see section 1.8).
- by examining the geographical distribution within a state (e.g. NSW) of a range of healthcare resources which are used by children (see section 1.12);
- by surveying a selection of the population of households which have at least one child about their experiences in accessing healthcare for that child (see section 4.6 and Chapter 5); and
- by hearing in their own words, by means of an interview, their experiences in accessing healthcare for their child (see sections 4.6, 4.7 and Chapter 5).

To address the fourth point first, the candidate interviewed the parents of children who had required admission to hospital within the last 12 months. Specifically, these were the parents of children with one of the ACSCs (see section 1.8) for which hospital admission rates of rural children in Australia are greater than those of urban children: complications of diabetes mellitus. The complications of diabetes were chosen because they occur relatively commonly and can lead to repeated contacts with the healthcare system, so that more episodes of interaction could be available for discussion during interview. Section 4.9 below describes the reasons for using interviews to gain information from participants, and the reason for using semi-open interviews.

4.5 University of Melbourne Human Research Ethics Committee Standard Project Application

Before invitations to participate in interviews could be sent, a Standard Project application was made to the Faculty of Health Sciences Human Research Committee. After modifications to the protocol (requested by the Department of General Practice Human Ethics Advisory Group) were made, the project was approved by the Human Ethics Sub-Committee of the University of

Melbourne's Faculty of Medicine, Dentistry and Health Sciences (Human Research Ethics Committee (HREC) Application no. 1647542) – see Appendix 8.

4.6 Invitation to rural NSW parents to participate in interviews

Table 9 shows the measures adopted to recruit parents to participate in interviews. GPs' surgeries and paediatricians' rooms in Western NSW were contacted by email or telephone, requesting that they display flyers describing the project and inviting parents to participate in brief (30–60 minute) interviews, either in person or by telephone. There were few responses from individual doctors' surgeries, and few responses from interested parents. Several organisations were very helpful in advertising and distributing flyers (see Table 9), but few contacts with parents ensued.

One direct contact made with a parent living in an Inner Regional area of NSW resulted in an interview. All of the four parent interviews were conducted by telephone. Telephone interviews are discussed in section 4.14. Because so few interviews with rural parents were achieved, they were not analysed according to themes, but rather are presented as individual examples. In order to obtain information on the experiences of rural families in obtaining healthcare for their child, and in view of the difficulty encountered in securing a sufficient number of interviews with parents, patient experience data from the NSW Child Population Health Survey (NSWCPHS) was employed. Points made by the parents who participated in interviews are used in sections 5.1-5.5 to illustrate issues that arose from analysis of the NSWCPHS.

TABLE 9 ATTEMPTS MADE TO RECRUIT PARENTS OF CHILDREN WHO HAD BEEN ADMITTED TO HOSPITAL FOR ACUTE GASTROENTERITIS OR FOR COMPLICATIONS OF DIABETES IN THE PREVIOUS 12 MONTHS

Organisation	Contacts sent		Outcome
Diabetes NSW	12E; 1P	Advertisements in newsletter and on Facebook page	1 interview
Royal Flying Doctor Service NSW	1E	No reply	nil
Royal Far West	2E; 1P	No consent from RFW ethics committee	nil
Agency for Clinical Innovation (ACI)	2E	Sent flyers to the following 4 networks	
Sydney Children's Hospital Network	3E	Flyer sent to doctors' surgeries throughout the network	nil
Sydney Children's Youth Advisory Group	Contact via ACI	Flyer sent to doctors' surgeries throughout the network	nil
Transitional Network	Contact via ACI	Flyer sent to doctors' surgeries throughout the network	nil
Rural Health Network	Contact via ACI	Flyer sent to doctors' surgeries throughout the network	nil
School of Rural Medicine, UNE	2E	Flyer sent to doctors' surgeries throughout the network	nil
Paediatrician 1 Armidale	3E	Distributed patient packs (plain language statement + consent form)	2 interviews
Paediatrician 2 Armidale	2E	Referred my request to Paediatrician 1 Armidale	
Paediatrician 3 Wagga	1E	No reply	nil
Paediatrician 4 Dubbo	2E	No reply	nil
Paediatrician 5 Orange	2E	No reply	nil
Paediatrician 6 Orange	2E	No reply	nil
GP surgery 1 Narrabri	2E	No reply	nil
GP surgery 2 Grenfell	1E + 1P	No reply to email	nil
GP surgery 3 Grenfell	1E + 1P	No reply to email	nil
GP surgery 5 Condobolin	1E + 1P	No reply to email	nil

GP surgery 5 Lake Cargelligo	1E + 1P	No reply to email	nil
GP surgery 6 Moree	1E + 1P	No reply to email	nil

E = email sent; P = phone call made to a medical practice

4.7 NSW Child Population Health Survey 2011–14: Data on patient satisfaction with health services

Data collected on patient satisfaction with health services, from a sample of NSW households with at least one child which participated in the annual NSWCPHS (conducted by the Centre for Epidemiology and Evidence (CEE) in the NSW Ministry of Health) between 2011 and 2014 was used to address research question 2. The NSW Population Health Survey (of which the NSWCPHS forms a part) samples 1,000 individuals each year from each of the eight LHDs, which between them cover all of NSW (i.e. 8,000 individuals are surveyed per year). In doing this, it samples approximately 2,000 households per year with at least one child aged 0–15 years. The responses of an individual adult parent or carer (aged 16 years or older) from these households was used for this analysis. Although, as described in section 1.11, a child becomes progressively more competent during late childhood and adolescence and individuals develop competence at different ages, for the purposes of this survey, a cut-off age for the end of childhood had to be selected, below which the child is more dependent and less likely to be able to give a reliable account of difficulty in obtaining access to healthcare, and at or above which an individual is less dependent and more likely to be capable of taking responsibility for the care of a child. For this survey, the CEE defines a responsible adult as someone aged 16 years or older. The responses, given by the adult on behalf of the child, refer to the family's experiences of obtaining access to healthcare for the child. In and before 2011, potential participant households were selected by random digit dialling to fixed line telephones within each LHD stratum. Since 2012, a random selection of valid Australian mobile phone numbers owned by individuals resident in NSW has been made, also using random digit dialling (343). Trained interviewers conduct the survey by telephone.

De-identified data from the NSWCPHS were requested from the CEE. This dataset contained responses to a subset of questions of the annual NSW Population Health Survey for the years 2011 to 2014 inclusive. These were the last years in which questions on patient satisfaction with health services were included in the survey, and were the first years for which the analysis of results of the survey had not been published. The CEE weighted the responses of each individual to adjust for differences in the probability of selection among subjects and for differences in response rates by gender and age (343). Table 10 shows the numbers sampled and the numbers of households with at

least one child by level of remoteness. Appendix 9 sets out the column headings in the dataset, the description of the items and range of values for each item.

TABLE 10 NUMBER AND PERCENTAGE OF NSW HOUSEHOLDS WITH AT LEAST ONE CHILD SURVEYED, BY REMOTENESS CATEGORY

Remoteness category	Households with at least one child		Questionnaires distributed	Survey respondents	Eligible households surveyed
	n	Col %	n	n	Row %
Major cities	529,702	74.4%	4,736	4,049	0.76%
Inner regional	136,483	19.2%	2,365	2,055	1.50%
Outer regional	41,788	5.9%	980	828	1.98%
Remote	2991	0.4%	61	58	1.94%
Very remote	799	0.1%	34	28	3.50%

Demographic data from ABS (2011) Census of Population and Housing (344)

n means count; Col % means column percentage; Row % means row percentage (the denominator is the total number of respondents in NSW)

Survey questions on patient satisfaction with health services

For each of eight types of service (e.g. GP, ED, hospital(345) – see Appendix 6), participants were asked if they had experienced difficulties getting healthcare when the child needed it. If they reported a difficulty, the free text description of that difficulty was then categorised by CEE staff as, for example, "Difficulty in accessing specialist services" or "Transport issues"(346) (see Appendix 7). Respondents were asked to rate their last contact with each type of health service on a five-point Likert scale (*excellent*, *very good*, *good*, *fair* or *poor*). Responses on the Likert scale were collapsed to a binary response (*fair*/*poor* versus *excellent*/*very good*/*good*) for each service type. When respondents rated a service as *fair* or *poor*, they were asked to provide a reason for that assessment. The free text responses were categorised by CEE staff as, for example, "Long waiting time" or "Poor technical skill of staff"(346) (see Appendix 7).

Levels of remoteness

Level of remoteness was categorised as Major City, Inner Regional, Outer Regional, Remote or Very Remote (see Appendix 1). The Major City category included Sydney, Newcastle, Wollongong and the Central Coast. Inner Regional contained large towns such as Dubbo, Orange and Mudgee, which

have substantial healthcare resources needed by children. When examining the experiences of families in more remote areas, it is important that their data should not be diluted by data from more numerous respondents from better-equipped Inner Regional areas. The more sparsely populated areas supplied fewer responses to the survey than Major Cities and Inner Regional areas, so for this analysis of satisfaction with health service across the different levels of remoteness, responses from Outer Regional, Remote and Very Remote areas were combined into the category "Rest of State" (ROS) to obtain more reliable estimates of healthcare experiences.

Statistical analysis

Data from the 2011–14 NSWCPHSs were imported into Stata 15 (347) statistical software for analysis. Counts and percentages of respondents by level of remoteness and counts and percentages for satisfaction with each of the eight healthcare service types by level of remoteness were obtained. For each of the eight service types, logistic regression was used to examine the association between the likelihood of experiencing difficulty in accessing healthcare for the child (binary response) and the level of remoteness (categorical variable), with Major Cities as the reference category. The "Survey" command in Stata was used to allow for the CEE's probability weights in logistic regression.

The odds that a respondent (weighted, as noted above) in a major city would report that they had difficulties getting healthcare when their child needed it were calculated as the number in the sample from major cities (weighted as described above) who reported difficulties of access divided by the weighted number in the sample who did not report such difficulty. Similarly, the odds of reporting a difficulty were calculated for respondents in the samples from Inner Regional areas and from Rest of State.

The ratio of the odds of Inner Regional respondents reporting access difficulty to the odds of Major Cities respondents reporting such difficulty was calculated. The 95% confidence limits for that odds ratio were then calculated. The 95% confidence limits define the range within which one could be 95% certain that the true odds ratio would lie if one sampled the entire population of households of each area. This process was repeated for Rest of State respondents compared with those of Major Cities respondents.

Of those who reported that they encountered difficulty, the type of difficulty by degree of remoteness was then examined. The types of difficulty were given as free text responses in the NSWCPHS, then coded by CEE staff into 13 categories (see Appendix 10). The odds ratio (and 95% confidence limits) of Inner Regional to Major Cities respondents and of Rest of State to Major Cities respondents was calculated for each type of difficulty.

The subjective assessment by respondents, broken down by level of remoteness, of eight types of healthcare service (Appendix 10) was examined. Respondents could rate their last contact with each type of service as *Excellent*, *Very good*, *Good*, *Fair* or *Poor*. The ratio of the odds of Inner Regional respondents describing a service as *Fair* or *Poor* to the odds of Major Cities respondents describing the same service as *Fair* or *Poor* were calculated, together with the 95% confidence limits for that odds ratio. The same odds ratio and 95% confidence limits were calculated for each of the eight types of health service. The same process was repeated to compare experiences of Rest of State respondents with those of Major Cities respondents.

When a respondent assessed a service as *Fair* or *Poor*, the NSWCPHS asked the reason for that assessment, and reported the responses by level of remoteness. These reasons, given as free text responses, were coded by CEE staff into categories.

The next sections describe the rationale behind interviewing government officials and advisers whose work involves making decisions about the allocation of healthcare resources that affect rural children or giving advice about those decisions. Later sections describe the conduct of the interviews and the analysis of data obtained from the interviews.

4.8 Resource allocation at which level of government?

In Australia, different aspects of healthcare are distributed and organised by federal, state and local governments and by government departments such as Health, Education and Social Services, but the major RA decisions are made within Departments of Health. Some healthcare resources – including GP services, some allied health services and paediatrician services – are provided by private practitioners. Decisions about the location and nature of these privately provided services lie outside the purview of government. The way in which responsibility for provision of healthcare services in Australia is shared is explained in more detail in Appendix 4. Although the problems of unequal distribution of healthcare resources and unequal health outcomes between rural and urban populations occur throughout Australia and tend to be treated as a national problem by commentators (348), in fact the RA decisions which lead to this maldistribution are made primarily at state level, although some are made within the Australian Government Department of Health (known as the Australian Federal Department of Health and Ageing when the data for this research were collected) (349).

As Kirigia reported in 2009, officials at regional level have little scope for allocating resources to achieve distributional equity (265). In order to gain an overall picture of the ethical assumptions which guide such decision-making, the candidate interviewed healthcare decision-makers and

advisers in the Australian Federal Department of Health and Ageing, as well as officials of the NSW Ministry of Health, both from Head Office in North Sydney, and regional officials from the Western NSW and Far West (NSW) LHDs.

4.9 The role of interviews with decision-makers

The ultimate power to make decisions about allocation of funds to programs lies with the parliament of each federal or state jurisdiction in Australia. These decisions are enacted by appropriation bills which can only be presented, for parliamentary approval, by the Government. The Annual Appropriations Bills, tabled with the Budget, allocate funds (approximately 25% of government expenditure in the case of the Australian Government) to ongoing programs and to new programs approved by Parliament within the Budget. As noted in section 2.5, 75% of federal government expenditure is authorised by Special Appropriations Bills, each of which requires an separate Act of Parliament which sets out the purpose and manner of use of the funding allocation (256, 350). In NSW, there are supplementary funding sources, some of which require parliamentary approval, while others such as Treasurer's Advances increase in response to changes in Commonwealth Special Purpose Payments, and Supplements with Offsetting Saving are administrative funding reallocations authorised by existing legislation, but which require ministerial approval (257).

Although, as this outline shows, authority for allocation of funds to projects is vested in Parliament and in cabinet, officials of the various government departments have a major role in offering advice on the allocation of funds and in assembling the evidence and the arguments which inform those allocation decisions. They also have some discretion over the allocation of funds as prescribed by the relevant appropriations bill. Although some macro-scale decisions which affect the allocation of healthcare resources are made by policy committees of the governing political party and expressed in the promises which the party takes to elections, much of the advice which informs decisions on the allocation of healthcare resources is provided by unelected officials of health departments. To understand the considerations (and in particular the ethical considerations) taken into account by Australian healthcare RA decision-makers, the most suitable approach was to conduct interviews with decision-makers, either individually or in pairs. For discussion of the dynamics of interviews with pairs of interviewees, see section 4.14. The following section describes why a phenomenological approach was adopted to elucidate the officials own experience of making RA decisions and of the role of their own moral principles in making them.

Why a phenomenological approach?

Phenomenology is a philosophical standpoint and a group of qualitative research methodologies which are concerned with the manifestation in the individual's own experience, of phenomena (including their ethical principles and the contribution of those principles to that person's decision-making)(351, 352). It was adopted here because the present study focuses on the moral beliefs and moral motivation (see section 8.14) of individual decision-makers(353). Methodologies such as heuristics(354) which focuses on the external observation (by the investigator) of phenomena, including the accounts of participants, rather than emphasising the experience from the participants' points of view, appeared not to fulfil the intention of the current study. Similarly, interactionist theory which is concerned with the behaviours and attitudes of groups and of individuals in relation to groups(355), does not appear to capture the essential focus of the present study on the experience of individual decision-makers of their own moral beliefs and the influence of those beliefs on their decision-making.

Why interviews?

Patton 2002 pointed out that "we interview people to find out from them those things that we cannot directly observe" (356). It may have been possible to find information on the official roles of participants in RA decision-making by consulting other sources, such as departmental documents. However, information on their reasons for doing what they do, for making the decisions they and their colleagues make and for offering the advice that they offer, based on their worldview, could only be obtained by asking them to discuss these areas; that is, by interviewing them.

Why semi-structured interviews?

As described in the introduction to Chapter 6, exploration of the ethical assumptions which guide healthcare resource decision-making in relation to children and to rural people requires examination of several areas. One way of doing that would be to use a structured interview, asking the same (mostly closed-ended) questions of all participants in the same order (357) to minimise bias, on the assumption that there is some objective truth to be discovered about the issues under examination, and that a researcher can gain some knowledge of that truth by ensuring that the questions asked of all respondents are the same, and that their responses can be summarised by the same repeatable method. This is essentially a positivist assumption (356, 357).

For the purposes of the current investigation, a structured interview had the disadvantage that closed-ended questions limit the range of response available to participants so that much relevant information may not be revealed about the areas of interest. As the purpose of the decision-maker

interviews in the present study was to reveal the range of ethical assumptions informing decision-making by Australian officials, rather than to establish the "real world" frequency or prevalence of ethical beliefs among Australian healthcare decision-makers, a phenomenological approach seemed more suitable than a positivist one (356). For this reason, a semi-structured approach to interviews was adopted, using an interview guide (356) (Appendix 11) to ensure that the topic areas relevant to the current investigation were discussed.

The questions did not use the same wording for each participant, but instead were guided by experience gained from previous interviews, the participant's responses to previous questions and by the work role of the participant. The questions asked were mainly open-ended in order to avoid limiting the participants' responses.

4.10 Identifying the decision-makers: invitations to interview

In order to gain insight into healthcare RA decision-making at the level of political parties and of elected members of the executive (i.e. health ministers), I telephoned the NSW headquarters of the Liberal and Labor parties and in each case was referred to the parliamentary office of the minister or shadow minister. Therefore, invitations to take part in interviews were emailed (attaching the project's Plain Language Statement, a statement of the information desired from an interview, and a Consent Form) to the parliamentary offices of two current state ministers of health, one former federal minister for health and one current state shadow health minister. I also emailed the personal assistant of a former state health minister. As Table 11 shows, the former federal health minister declined an interview and one of the current state health ministers referred the invitation to officials of the health department; there was no reply to the other invitations.

The websites of the Federal Department of Health and Ageing, the Victorian Department of Health (now the Department of Health and Human Services) and NSW Ministry of Health enabled identification of senior officials whose titles suggested that they were involved in RA decisions or in giving advice to inform such decisions. Elected and non-elected members of the Victorian Department of Health were emailed, but no replies were received. The public relations section of the Victorian Department of Health was emailed and called by telephone to obtain contact details of named senior Department officials, but no reply was forthcoming. The suitability of Victoria as a location for the study (see section 4.1) was therefore reviewed and NSW adopted as the location of study. Emails were sent to the personal assistants of elected and non-elected officials of the NSW Ministry of Health (including officials from Head Office, as well as from the Western NSW and the Far West LHDs, whose position titles suggested a role in decision-making about healthcare RA). In addition, the personal assistants of senior officials of the Federal Department of Health and Ageing

were contacted to request the participation of those officials in an interview. Each email contact included a Plain Language Statement of the project and a Participant Consent Form, giving details of measures to be taken to preserve the privacy and anonymity of participants. Details of these communications are shown in Table 11.

TABLE 11 REQUESTS FOR INTERVIEW –ELECTED AND NON-ELECTED MEMBERS OF HEALTH DEPARTMENTS

Position of the invited interviewee	Location	Contacts	Outcome
Senior officials	WLHD	5E	Tel Interview
Senior official	FWLHD	2E	No interview
NSW Minister for Health	NSWMH	1E	Interview with Parliamentary Sec. for Rural Health
Retired NSW Minister for Health	NSWMH	1E	Tel Interview
Senior official	FWLHD	4E	Tel interview
Senior officials	Head Off.	5E, 3Ph	No interview
Health consultants	Orange	5E	Tel Interview
Senior official	Head Off.	2E	No reply
Senior official	Head Off.	2E	No reply
Senior official	Head Off.	1E	No reply
Senior officials	FWLHD	1E	No reply
Senior official	FWLHD	1E	No interview
Senior official	Head Off	2E	No reply
Senior official	Head Off	1E	No reply
Senior official	FWLHD	2E	No reply
Senior official	Head Off	3E	No reply
Senior official	FWLHD	2E	No interview
NSW Shadow Minister Health	NSW Parlt	1E	No reply
9 senior officials	Vic Health	1E, 1Ph	No reply
Vic Minister for Health	Vic Health	1E	No reply
4 Senior managers and advisers	Fed D H&A	1E	4 interviews incl. below
Senior managers	Fed D H&A	3E, 2Ph	2 interviews
Senior managers and advisers	Fed D H&A	3E	2 interviews
Ex Vic Minister of Health	Vic Health	1E	No reply
Ex Federal Minister for Health	Fed D H&A	1E	No interview

Fed D H&A = Australian Government Department of Health and Ageing; FWLHD = Far West (of NSW) Local Health District; Head Off. = the head office in Sydney of the NSW Ministry of Health; NSWMH = = NSW Ministry of Health; NSW Parlt = Parliament of the State of NSW; Orange is a regional city in NSW; E = email; Ph = telephone call.

Table 12 describes the 51 emails and six telephone calls needed to arrange three individual interviews (two face-to-face and one telephone) and three interviews with two participants each (one face-to-face and two by telephone).

TABLE 12 INTERVIEWS CONDUCTED WITH FEDERAL AND NSW HEALTH DEPARTMENT OFFICIALS AND ADVISERS

Interview type	Participants	Date	Affiliation
Face to face	1	17/11/2016	Federal Department of Health and Ageing
Face to face	1	17/11/2016	Federal Department of Health and Ageing
Telephone	1	15/3/2018	Far West NSW Local Health District
Face to face	2	12/12/2016	Federal Department of Health and Ageing
Telephone	2	19/2/2018	Western NSW Local Health District
Telephone	2	14/2/2018	KBC Pty Ltd: advisers to Federal & State Depts of Health
Telephone	1	6/6/2018	Retired NSW Minister for Health
Face to face	1	17/4/2018	NSW Parliamentary Secretary for Regional and Rural Health

4.11 University of Melbourne minimal risk ethics application

In order to interview officials of the NSW Department of Health and the Australian Department of Health and Ageing, it was necessary to gain consent from the University of Melbourne's HREC. As this part of the project satisfied the criteria which define a Minimal Risk application, the Committee approved it (with minor modifications to the original application) see Appendix 12. No further ethics committee approval was required to interview officials of the Australian Department of Health and Ageing.

4.12 NSW Health ethics application and site-specific ethics applications (SSAs)

To interview officials of Local Health Districts in NSW (including Western NSW LHD and Far West LHD), approval was obtained from the HREC of the Western NSW Local Health District, and further approval via site-specific ethics applications for interviews in Dubbo and Broken Hill. No HREC application or ethics approval was required for interviews with officials in the Head Office of the NSW Ministry of Health in North Sydney.

4.13 Identifying the issues to be explored in interviews with resource allocation decision-makers

Section 1.3 sets out the research questions which this study was designed to answer. In particular, the aim of interviews with decision-makers was to understand how they saw the role of ethical principles in decisions about allocating healthcare resources or in giving advice to inform those decisions. The interviews with decision-makers aimed to elicit information about the officials' role in the decision-making process and their views on the duties of a government to those whom it governs; their views on what characterises a good RA decision; the treatment of individuals or groups with expensive healthcare needs; and whether the needs of children or rural people should be treated differently from those of others (see Appendix 11). In later interviews, the introductory questions were modified, based on the responses of participants in earlier issues, in order to focus on or clarify some portions of the data.

4.14 Process of interview

Face-to-face interviews were arranged with four senior officials of the Federal Department of Health and Ageing by discussion with their personal assistants. These took place in their offices in the Department in Canberra on 17/11/2016 and 12/12/2016. Two of the interviews were with a single participant, and one was with two participants. Minichiello et al. refer to interviews involving a single interviewer and two participants as "group interviewing" (357). In the present study, each case of group interviewing was determined by the participants as a condition of their participation.

Group interviews

An advantage of group interviewing, apart from increasing the likelihood that officials may be more willing to participate if they feel supported by a colleague and protected from problems that might attend the revelation of their private opinions, is that the participants may amplify each other's ideas, and thereby extend the range of discussion about each topic area. It may be, even among educated and senior people such as the participants in the current study, that there are ideas and topics which are acceptable to discuss when there are two or more participants but which a single participant may not wish to raise (356). Interviewing two participants in the same interview may elicit different kinds of information from each, and each may remember and contribute different details about the same event or situation (357).

Differences in role, power and personality between participants, however, may mean that the views of one dominate those of the other in a group interview, making it less likely that the views of the less dominant would be heard than would be the case in individual interviews. Conflicts of interest

between the participants may impede the clear expression of the views of each individual (357), and political relationships within a department may mean that the presence of a colleague reduces the likelihood that private views are expressed. These disadvantages may be amplified when the group interview is conducted by telephone, because the possibility of muting possible sources of conflict between the participants by means of reassuring body language is unavailable in telephone interviews.

Telephone interviews

Several of the interviews, both with health department officials and with parents of rural children, were conducted by telephone due to the large distances between interviewer and interviewees (several of whom were located in remote areas of western and northern NSW). The interviewer called from a private office with the door closed, with the speaker phone activated and the interview recorded digitally (with prior verbal agreement of the participant). Telephone rather than face-to-face interviews were requested by each of the parents interviewed, by all of the officials located in Western and Far West NSW LHDs, and a teleconference was requested by the officials located in the Head Office of the NSW Ministry of Health in North Sydney. In each case, telephone interview was requested to increase the flexibility of time of interview, to allow for the fact that the officials' schedules were busy and new commitments could arise unexpectedly.

Telephone interview is a method commonly used for administration of interviewer-assisted surveys and structured interviews (357, 358), but is less commonly used for in-depth or semi-structured interviews (359). Use of telephone interviews can reduce both travel time and cost and may facilitate access to participants, especially those who are very remotely located and who might otherwise be completely inaccessible and whose stories, information and opinions might remain unheard (359, 360). Potential participants who might be reluctant because of transport, health or other difficulties to participate in a face-to-face interview may agree to a telephone interview. A telephone interview may be perceived by some participants as offering greater anonymity than a face-to-face interview (360, 361) which may be an inducement to participation, especially when the topics to be discussed are seen as sensitive (360).

The absence of visual cues in a telephone interview, however, may either encourage or inhibit the revelation of information. The telephone interviewer is then reliant on verbal cues to express interest in what the participant is saying or to encourage further expansion on the topic (362). While earlier texts on interview technique suggested that the quality of data that can be obtained from telephone interview was more limited than that obtainable in face-to-face interviews because of the lack of visual cues, the lack of "presence" of the interviewer and the lack of the quality of

interpersonal conversation, comparative studies by later researchers found no significant differences in the quality or quantity of information obtainable (360, 363). A study of participants' experience of telephone interview noted that most found it a positive experience, although when the author was deliberately reticent, many participants found the interaction "difficult" (363) and more dependent on verbal cues from the interviewer, which may in itself affect the quality of data obtained. Stephens found that when interviewing "elites and ultra-elites", telephone interview permitted less frequent but more directive guidance of the conversation (364) because of the very senior status of the macro-economists whom he interviewed. This finding is relevant to the present study, in that many of the officials interviewed had a very senior role in their department, and most interviews included a few clear changes of topic, each of which elicited a prolonged, wide-ranging discussion.

Recording and transcription of interviews

Each interview was recorded on a digital voice recorder and transcribed, some by the researcher and some by a third party. The intention of the transcripts (and the instruction to the third party transcriber) were to record the direct speech of the participant and of the interviewer, without attempting to record variation in the speakers' tone, length of pauses or non-verbal sounds (365), because the aim of the interviews was to hear the expressed views of the participants, rather than, at this stage, the researcher's interpretation of their views. Interpretation of the expressed views was undertaken later, in the analysis phase of the study (see section 4.15). The transcript of each interview was compared to the recorded interview to ensure that it reflected the speakers' words, and any corrections to the transcript which were needed were then made.

Storage and privacy

Digital versions of interviews were retained on University of Melbourne servers to which only the researchers (the PhD candidate and his supervisors in the University of Melbourne Department of General Practice) had the password. Any other digital copies of the interviews were then destroyed. Hard copies of the transcripts of interview were retained in a locked filing cabinet in the Department of General Practice in the University of Melbourne, to which only the researchers held a key.

4.15 Analysis of the data

The dataset consisted of the recorded and transcribed text of all interviews. When interpreting the data to elucidate the issues described in section 4.13, the candidate adopted the method of thematic analysis described by Braun and Clarke (2006) (366). Thematic analysis is "a method for identifying, analysing and interpreting patterned meanings or 'themes' in qualitative data" (367). This approach to data analysis was adopted because it appeared to offer the most flexible means of

gaining a picture of healthcare RA decision-making as those who make the decisions see it: its participants; its methods and the considerations that are taken into account when decisions are made. The flexibility of thematic analysis is due to it being limited to describing procedures for coding data, creating themes among those codes and for producing a written description and interpretation of the picture which emerges from the themes (367), without requiring adherence to a particular theoretical framework. Nonetheless, it is inevitable that any researcher will bring to the research some prior knowledge and ideas, as well as knowledge and ideas gained from study of the literature on the subject. This prior information and the prior impressions gained will always affect the questions asked in interviews; the interviewer's response to the interviewees' replies, the selection of important sections of data to code, and the themes identified or created from those codes (366).

First phase of thematic analysis

The form of thematic analysis that Braun and Clarke (2006) describe consists of six phases: familiarising oneself with the data; generating initial codes; searching for themes; reviewing the themes; defining and naming the themes; and producing a report (366). In the first phase, each recorded interview was listened to and compared to the transcript, to ensure that the transcript adhered to the sense of the spoken interview as described in section 4.14, then the manuscript was re-read to familiarise the researcher with the data.

Second phase

The data were then examined, and descriptive codes assigned to segments of the transcripts. A code in this sense, is a word or phrase which describes or gives an overview of the content of that segment of the data (368). The coding system used was that described by Saldana (2009) as "initial coding" (368), in which the codes "break down the data into manageable pieces" (369) and represent reflection on the meaning of the individual segments of data (368, 369). In the present study, an inductive approach was adopted to coding. That is, the codes were discovered within the data as successive interviews were analysed, rather than being determined before analysis of the data (deductive coding) (356). Codes were assigned to individual pieces of data which were relevant to the issues being investigated (the participants in decision-making about healthcare RA, how decisions are arrived at, the considerations that are taken into account when decisions are made – in particular, ethical assumptions and the attitudes of decision-makers to children and to rural people). A list of codes, the pieces of data to which they referred and the participants who contributed those pieces of data were kept in an Excel file.

Third phase

For each category, a mind map was constructed (using MindMup 2 via Google Docs online). In these mind maps, potential themes which had been identified among the lists of codes in the Excel file described above were linked to the relevant codes. New themes which appeared during this process were added to the mind map, and connections between related themes were made (366).

Fourth phase

The themes in the mind map of each category were re-examined and when necessary, renamed. During this revision process, connections of codes to the original data extracts stored in the Excel file were re-examined and modifications made to the names of themes and to their place in the overall picture. A verbal description of the resulting themes and their linkages appears in Chapter 6.

Fifth and sixth phases

In the fifth phase of the analysis, each theme was examined and an account of the different aspects of each them was developed. Each account incorporated an examination of the role which each theme, and each aspect of the theme, plays in the overall story revealed by the data. These accounts and the way in which they relate to each other, are set out in Chapter 6. The results of the sixth phase of the analysis described by Braun and Clarke, the production of the report of the study and its analysis (366) are set out in chapters 6, 8 and 9 of this thesis.

The following three chapters describe the results of the study. Chapter 5 reports the findings of the study of locations of healthcare resources for children in Western NSW and results of analysis of parental experiences in obtaining healthcare for their child. Chapter 6 presents findings from analysis of the interviews with healthcare decision-makers on the process of RA decision-making. Chapter 7 reports findings about the ethical rationale behind the RA decisions which led rural parents to have the experiences they described.

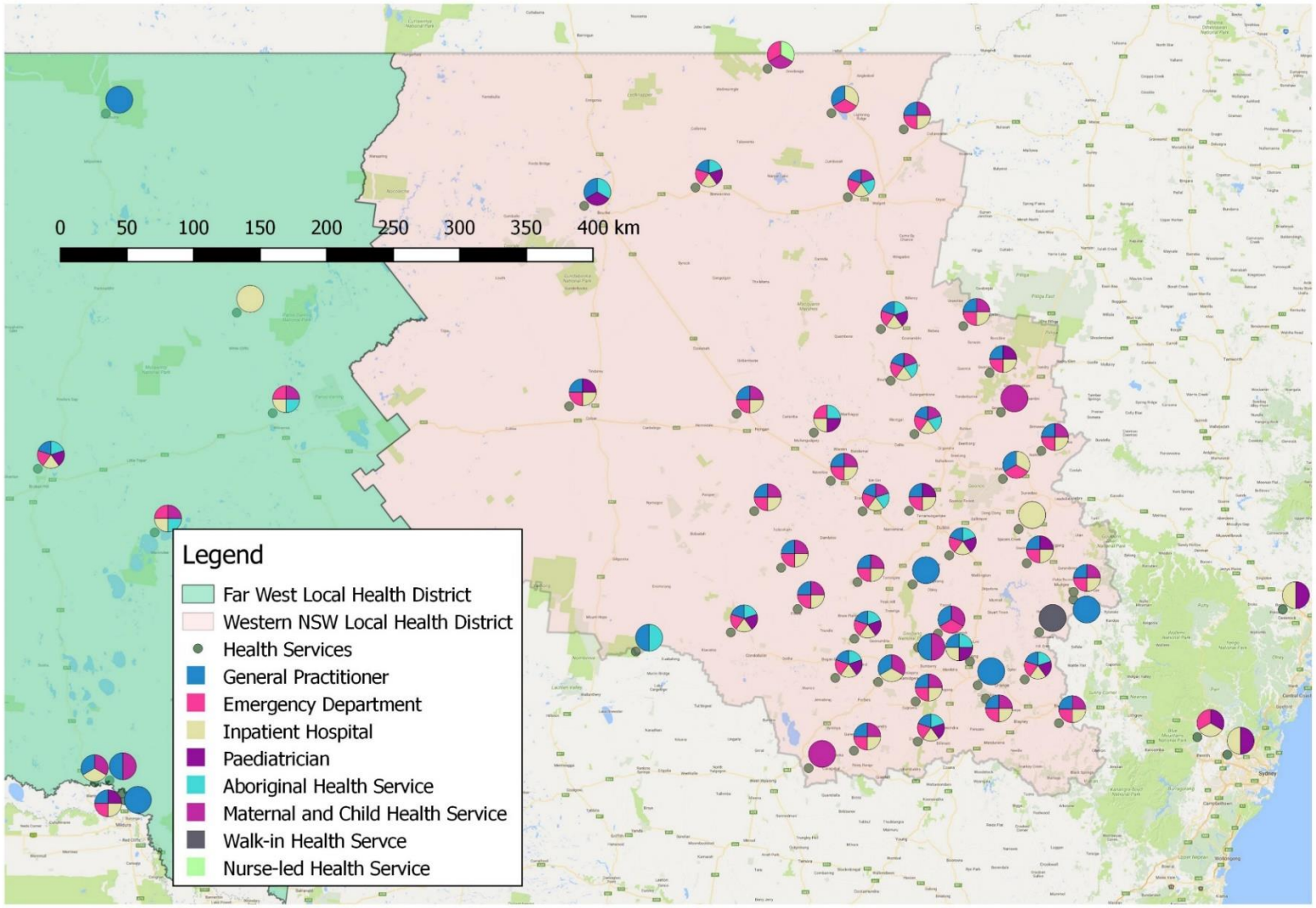
Chapter 5: Results: Healthcare resource distribution and experiences of NSW parents in accessing healthcare for their child

The first part of the chapter describes the findings of the study of location of healthcare resources for children located in Western NSW. The second part of the chapter describes the results of analysis of survey data from the NSWCPHS 2011–14 and illustrates the findings with quotes from interviews of rural parents.

5.1 Distribution of healthcare services for children in Western NSW

While the provision of many health-related services in Western NSW affects the health and the healthcare of rural children (for example dental services, dermatology services, child and adolescent psychology, rehabilitation services, palliative care, dietetics and wheelchair rental services), only a selection of commonly used child healthcare services is examined here (Tables 13–16 and Figure 5). The term "Western NSW" as used here refers to the whole west of the state of NSW. Several government departments in NSW divide the state into segments of which the boundaries do not always correspond between departments. Thus, the term "Western NSW" as used in this chapter, includes the two NSW Health divisions: Western NSW LHD and Far West LHD. Two hundred and sixty-one SSCs cover the whole of Western NSW. SSCs in Western NSW vary in area from 0.44 km^2 (South Littleton, a suburb of Lithgow) to 19851.86 km^2 (Wanaaring) and their population density in 2016 varied from zero in unpopulated SSCs to 1270.59 persons per km^2 in West Bathurst. Of these 261 SSCs, 34 had more than 2000 inhabitants in the 2016 census; 16 had 1000–2000; 33 had 500–999; 62 had 200-499 and 102 had < 200 inhabitants (370). Tables 13–16 show the numbers of children living in SSCs of different total population sizes.

FIGURE 5 WESTERN NSW, SHOWING LHD BOUNDARIES AND LOCATIONS OF HEALTH SERVICES FOR CHILDREN. DATA FROM THE AUSTRALIAN HEALTH SERVICES DIRECTORY



Tables 13–16 also show the distribution of healthcare resources between SSCs of different population sizes in Western NSW. Each of these tables shows the total number of children in SSCs of that population size, and the number (proportion) of SSCs of that population size which have child-relevant healthcare resources. It should be noted that while a resource is lacking in one SSC (e.g. West Bathurst), it may be available in one nearby (e.g. Bathurst). In some other cases, the function of a service which may not be present in the SSC (e.g. a maternal and child health clinic) may be performed by another facility (e.g. a GP or an Aboriginal health centre) available in that SSC. The tables show that even among SSCs of 2,000 or more inhabitants, 18% have no GP, and among SSCs of 1000–1999 inhabitants, 37% have no GP. In smaller centres of population, primary care services, including Aboriginal health centres, are even less commonly found, meaning that families must travel to larger towns for primary care.

Although hospital inpatient beds are available in some towns, only hospitals with 24-hour paediatric services (in Western NSW, that means Orange, Bathurst, Dubbo and Broken Hill) admit children overnight, but smaller centres will accommodate a sick or injured child pending the arrival of a transport service for retrieval to a paediatric centre. When a child requiring inpatient care lives in a town without a hospital or where the hospital does not admit children to inpatient beds, she or he must be transported to a nearby larger town such as Dubbo or Orange, or if tertiary paediatric care is needed, to Westmead Children's Hospital or Sydney Children's Hospital in Sydney, or to John Hunter Hospital in Newcastle.

TABLE 13 HEALTHCARE RESOURCES IN WESTERN NSW SSCS WITH 2000 OR MORE INHABITANTS

41,052 children in 34 SSCs	**SSCs with the resource**	**SSCs without the resource**
General practitioner	28 (82% of SSCs)	6 (18% of SSCs)
Paediatric service	15 (44%): 4 have 24-hour service	19 (56%)
Hospital inpatient beds	24 (71%): only 4 admit children	10 (29%)
Emergency department	7 (21%)	27 (79%)
Aboriginal health centre	14 (41%)	20 (59%)
Maternal and child health clinic	7 (21%)	27 (79%)
Walk-in clinic	8 (24%)	26 (76%

Data from ABS 1270.0.55.003 Non ABS structures (2016) (371), ABS Quick Stats (2016) (370) and National Health Services Directory (341)

TABLE 14 HEALTHCARE RESOURCES IN WESTERN NSW SSCS WITH 1000–1999 INHABITANTS

4061 children in 16 SSCs	**SSCs with the resource**	**SSCs without the resource**
General practitioner	10 (63% of SSCs)	6 (37% of SSCs)
Paediatric service	2 (13%)	14 (87%)
Hospital inpatient beds	6 (37%)	10 (63%)
Emergency department	3 (19%)	13 (81%
Aboriginal health centre	2 (13%)	14 (87%)
Maternal and child health clinic	2 (13%)	14 (87%)

Data from ABS 1270.0.55.003 Non ABS structures (2016) (371), ABS Quick Stats (2016) (370) and National Health Services Directory (341)

TABLE 15 HEALTHCARE RESOURCES IN WESTERN NSW SSCS WITH 500–999 INHABITANTS

4184 children in 33 SSCs	**SSCs with the resource**	**SSCs without the resource**
General practitioner	8 (24% of SSCs)	25 (76% of SSCs)
Paediatric service	0 (0%)	33 (100%)
Hospital inpatient beds	8 (24%)	25 (76%)
Emergency department	14 (42%)	19 (58%)
Aboriginal health centre	3 (9%)	30 (91%)
Maternal and child health clinic	15 (45%)	18 (55%)
Walk-in clinic	1 (3%)	32 (97%)

Data from ABS 1270.0.55.003 Non ABS structures (2016) (371), ABS Quick Stats (2016) (370) and National Health Services Directory (341)

TABLE 16 HEALTHCARE RESOURCES IN WESTERN NSW SSCS WITH FEWER THAN 500 INHABITANTS

5495 children in 164 SSCs	**SSCs with the resource**	**SSCs without the resource**
General practitioner	5 (3% of SSCs)	159 (97% of SSCs)
Paediatric service	0 (0%)	164 (100%)
Hospital inpatient beds	4 (2%)	160 (98%)
Emergency department	18 (11%)	146 (89%)
Aboriginal health centre	1 (0.6%)	163 (99.4%)
Maternal and child health clinic	22 (13%)	142 (87%)
Walk-in clinic	1 (0.6%)	163 (99.4%)

Data from ABS 1270.0.55.003 Non ABS structures (2016) (371), ABS Quick Stats (2016) (370) and National Health Services Directory (341)

Emergency departments in NSW are categorised by the NSW Ministry of Health according to their role and capabilities(372) . While the level of service assigned to individual hospitals is decided by the LHD in NSW, the capabilities and resources required of each level of service are determined by NSW Health Headquarters. Table 17 shows the location of EDs of the six levels of capability which serve children in Western NSW. Two of the three Level 6 EDs are located in Sydney and the third is in Newcastle. These locations and the distances between them can also be seen in Figure 5. The following section sets out the functions which NSW Health expects each level of ED to be able to perform and the facilities and services to which EDs of each level are expected to have immediate access.

Level 1 EDs are able to provide primary care assessment; they have staff onsite 24 hours per day who are able to provide basic life support to adults and children. They have formal relationships within the network, with higher-level emergency medical services for advice and education and formal plans for gaining emergency response assistance from NSW Ambulance or the Royal Flying Doctor Service. They do not necessarily have access to radiology, pharmacy or pathology services, nor to anaesthesia or operating suite services.

TABLE 17 LOCATION OF EDS OF EACH LEVEL OF CAPABILITY IN WESTERN NSW AND FAR WEST LHDS

Level 1 ED	Level 2 ED	Level 3 ED	Level 4 ED	Level 5 ED	Level 6 ED
Wentworth	Balranald	Broken Hill	Bathurst	Dubbo	Children's Hospital Westmead
Baradine	Wilcannia	Cowra		Orange	Sydney Children's Hospital
Blayney	Bourke	Forbes			John Hunter Children's Hospital
Brewarrina	Cobar	Mudgee			
Canowindra	Condobolin	Parkes			
Collarenebri	Coonabarabran				
Coolah	Coonamble				
Dunedoo	Lightning Ridge				
Eugowra	Warren				
Gilgandra	Ivanhoe				
Grenfell	Menindee				
Gulargambone	Tibooburra				
Gulgong					
Molong					
Narromine					
Nyngan					
Oberon					
Peak Hill					
Rylstone					
Tottenham					
Trangie					
Trundle					
Tullamore					
Walgett					
Wellington					

Data from NSW Health 2019 Role Delineation Levels of Emergency Medicine(372)

Level 2 EDs have all of the facilities of level 1 EDs, but in addition have nurses with extra training in emergency medicine and a medical practitioner on call at least during daylight hours. They have access to radiology, pathology and pharmacy services and 24-hour access to local and statewide retrieval and transport services (including the NSW Neonatal and Paediatric Emergency Transport Service, based in Sydney, the Greater Sydney Area Helicopter Emergency Medical Service based in Orange and the Royal Flying Doctor Service (fixed-wing aircraft) based in Dubbo and in Broken Hill). The role of Level 2 EDs is to perform assessment and care of acutely ill adults and children within their capability, plus assessment and stabilisation of critically ill adults and children, including trauma patients, pending the arrival of the retrieval service. They have access via telephone, telemedicine link or hospital outreach with surgical, medical, paediatric, psychiatric and obstetric and gynaecology services. They are appropriately equipped to perform advanced life support for adults and children, including trauma patients.

Level 3 EDs have all of the facilities and capabilities of Level 2 EDs plus access to anaesthesia and operating suite services. They have a medical practitioner with a basic level of postgraduate training in emergency medicine on call 24 hours per day. They have a separate, appropriately equipped area for paediatric assessment, management and resuscitation. They have documented guidelines for clinical management, including management of children. They have telephone, telehealth or tertiary hospital outreach access to tertiary level (i.e. subspecialty) paediatrics, including paediatric intensive care.

Level 4 EDs have all of the facilities and capabilities of Level 3 EDs plus specialist emergency medicine staff onsite and access to an intensive care unit within the facility. The ED itself may have a short-stay ward attached. Level 4 EDs are able to provide definitive care for most emergency conditions (other than those requiring sub-specialty care).

Level 5 EDs have all of the facilities and capabilities of Level 4 EDs plus 24-hour specialist emergency physician cover. Other specialty services (including general paediatrics, physiotherapy and social work services) are available onsite and after hours. Level 5 EDs have specific trauma resuscitation areas, a safe area for mental health patients and a short stay unit for monitoring and assessment. Level 5 EDs are capable of managing critically ill patients.

Level 6 EDs are able to manage all complex emergencies and to coordinate the provision of outreach care to lower-level EDs. They have onsite access to subspecialty services including neurosurgery, cardiothoracic surgery and, in the case of children’s hospitals, paediatric intensive care.

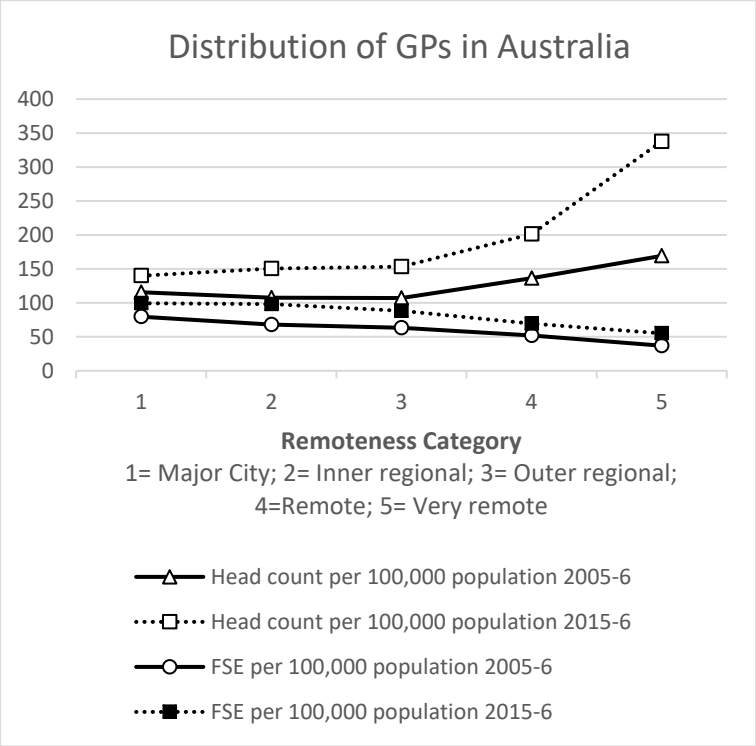
The availability of general practitioners in rural Australia

Figure 6 illustrates the distribution of Australian GPs by the remoteness of their practice location. It shows that although the number of GPs per 100,000 population increases progressively with increasing remoteness (a phenomenon seen even more clearly in 2015–16 than in 2005–06), the number of GP full-time equivalents in fact *decreases* with increasing remoteness. This means that more rural and remote GPs than urban GPs practice part-time. This phenomenon of part-time practice limits the number of hours per week when a GP is available, and consequently limits the access of rural children to their GP. Further, Figure 6 shows that although the head count of GPs practising in rural and remote areas is increasing, an increasing proportion of them is practising part-time, so that the number of full-time equivalents in rural areas is not increasing.

Distribution of paediatricians in Western NSW

In Western NSW as in the rest of Australia, paediatric services are centralised. Tertiary paediatric hospitals are located at Westmead in Western Sydney, Randwick in the eastern suburbs of Sydney, and in Newcastle. Staff of these hospitals provide outreach services in subspecialty- and general paediatrics to larger towns in rural NSW (Tables 13–16). Only Orange, Bathurst, Dubbo and Broken Hill have 24-hour general paediatric services, including ambulatory and inpatient care. As Fig. 5 shows, sessional services by visiting paediatricians are available in other, smaller towns in Western NSW. Those specialist visits may occur weekly, fortnightly or monthly, but that does not enable hospital inpatient care of children in those towns. Onsite and outreach services are supplemented by telemedicine (see Glossary) to varying extents across Australian states.

FIGURE 6 DISTRIBUTION OF GPS IN AUSTRALIAN TOWNS



Data from General Practice Statistics, Australian Department of Health (2016) (373)

Telemedicine services and rural paediatric care

A well-developed system of telemedicine services linking rural hospitals with the tertiary paediatric centres is established in NSW. Telemedicine is used for subspecialty consultation, for routine follow-up by a variety of subspecialists, and to aid diagnosis of acute illnesses when this requires visualisation by the subspecialist. It is especially useful for remote hospitals and for subspecialties with a paucity of specialists, such as child psychiatry (374, 375). Although there are evident benefits of telemedicine for individual families and individual rural hospitals, the economic benefits for the health system as a whole are uncertain (376), and telemedicine has certain definite limitations: the quality and reliability of clinical examination are dependent on the skill and experience of the clinician (nurse or doctor) present with the child (377); high-resolution video is important for physical assessment of the child but is not always available; issues of confidentiality and of legal responsibility for advice given and treatment decisions based on telemedicine consultation have yet to be satisfactorily resolved (375).

5.2 The experiences of rural families in accessing healthcare for children

The role of Australian governments, both federal and state, in determining the location, funding and organisation of healthcare resources is discussed in Appendix 4. Chapter 2 describes the process of rationing scarce healthcare resources. As the preceding sections have shown, healthcare services that are needed by children are distributed very unevenly throughout the large area of NSW (as they are in other states of Australia) and the distances which must be travelled by many children and families to access paediatric services and hospital inpatient care are very great.

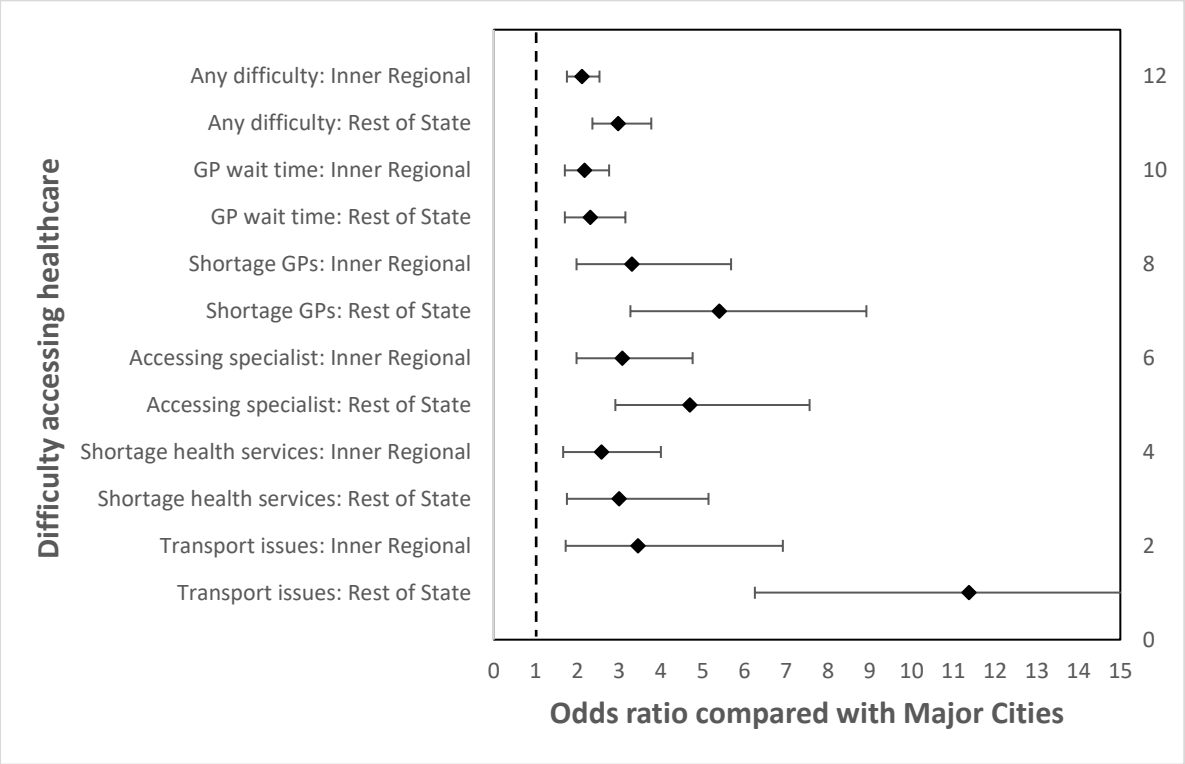
The NSWCPHS examined the experiences of families in urban and rural NSW in obtaining healthcare for their child. As described in the last chapter, the survey included opportunities for respondents to explain, in free text form, the reasons for their responses to survey questions (see Appendix 9). In this chapter, "urban families" refers to families from the Major Cities level of remoteness (see Appendix 1) and "rural families" refers to families from all other areas of NSW. In understanding the significance of family experiences reported in this survey, it should be remembered that while services such as EDs, Aboriginal Health Clinics and Community Nurses are established, allocated and funded by governments, most GPs and some paediatricians and allied health clinicians are private practitioners, which means that in Australia, their location, remuneration and hours of work (and therefore access to them) are not under the control of governments.

In this chapter, the findings of the Survey, expressed in numerical terms, are enhanced with information provided during interviews with parents from rural NSW. As shown in Chapter 4, there were four interviews (all by telephone) with parents. Three interviews were with mothers (one from Inner Regional NSW and two from Outer Regional NSW) and one interview was with both the mother and father of a child from Outer Regional NSW. Their children had chronic illnesses of durations between one and three years. To preserve the families' privacy and anonymity, the part of the state and the names of towns referred to in interviews are not shown here.

While almost 14% of 4736 urban parents surveyed described experiencing some difficulty in obtaining access to healthcare for their sick child (see Table 18), more than 22% of 2365 parents in Inner Regional areas and more than 29% of 1075 parents in Outer Regional, Remote or Very Remote areas (grouped in this analysis as ROS) experienced such access difficulties. Figure 7 plots the ratio (represented by a dot) between the odds of families in rural areas (Inner Regional or ROS) experiencing difficulty with selected health services and the odds of that difficulty being experienced by families in a Major City. The standard error bars indicate the 95% confidence interval (95%CI)

around that estimated odds ratio. Odds ratios greater than 1 indicate that families in rural areas were more likely to report difficulty accessing services than families living in Major Cities. An odds ratio (OR) of 1 is represented by the vertical line. Figure 7 shows that families from rural areas, whether from an Inner regional area or from an area more remote from major centres of population, were more likely than families living in a Major City to experience difficulty in obtaining healthcare access for their children.

FIGURE 7 ODDS RATIO WITH 95% CONFIDENCE INTERVAL OF PARENTS FROM RURAL AREAS (INNER REGIONAL OR ROS) REPORTING DIFFICULTY GAINING ACCESS TO HEALTHCARE SERVICES FOR THEIR CHILD COMPARED WITH FAMILIES FROM MAJOR CITIES



Data from the NSWCPHS 2011–14. N = 8176

Table 18 shows the counts and percentages of respondents to the NSWCPHS 2011–14 who reported difficulty in obtaining healthcare access for their child, by the level of remoteness of their domicile. The first line in the table shows those who reported *any* difficulty with at least one of the health services, and the subsequent lines show *which* difficulties were reported. The first three pairs of columns show the number and proportion of respondents who answered "yes" to each question. Note that the individual difficulties were not mutually exclusive: that is, a respondent may have reported more than one difficulty. The second-last pair of columns shows the ratio of the odds of Inner Regional families reporting an access difficulty to the odds of urban families reporting that

difficulty, and the 95%CI around that OR. The last pair of columns shows the same information for ROS families. Highlighted data show the access problems for which the 95%CI around the OR excludes the value 1.0.

5.3 Problems with general practitioners

While a shortage of GPs in the local area was not a common complaint, it was more commonly reported in rural than in urban areas (see Table 18). However, the main difficulty with GPs, experienced by families in urban as well as rural areas, was the long time children needed to wait in order to see a GP. As Table 18 shows, 6.8% of urban families, 11.4% of Inner Regional families and 13.2% of ROS families reported long waiting times. One of the interviewed parents also mentioned this problem:

> *There's a lady (a GP) there now that, she's the only one I ever see but it takes about two weeks to get in to her.* Parent C: Inner Regional

The apparent discrepancy between the high prevalence of long times on GPs' waiting lists on the one hand, and the infrequency of reports of lack of local GPs on the other, may be explained by the finding (described in section 1.11 and illustrated in Figure 3) that although the number of GPs per 100,000 population is increasing in rural areas, the number of GP full-time equivalents per 100,000 is considerably lower in rural than in urban areas of Australia and is not increasing, possibly because more rural than urban GPs work part-time, and this trend to part-time work is increasing. A reason for this may be the increasing number of female GPs (including those in their childbearing years) entering the rural GP workforce and the fact that female GPs work on average 8.1 fewer hours per week than their male counterparts (378). The wide range of roles of rural GPs compared with those of urban GPs (e.g. EDs, clinical procedures and public health roles) may reduce the time for which each rural GP is available for in-office consultations (379).

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TABLE 18 SUMMARY STATISTICS OF DIFFICULTY IN OBTAINING HEALTHCARE ACCESS FOR THEIR CHILD BY TYPE OF ACCESS DIFFICULTY BY LEVEL OF REMOTENESS AND ODDS RATIO (WITH 95%CI) OF INNER REGIONAL AND REST OF STATE FAMILIES COMPARED WITH MAJOR CITIES

	Major cities n = 4736		Inner regional n = 2365		Rest of state n = 1075		Inner regional		Rest of state	
	n	% Yes response	n	% Yes response	n	% Yes response	Odds ratio	95%CI	Odds ratio	95%CI
Experience any difficulty?	652	13.77	531	22.45	314	29.21	2.11	1.75–2.53	2.98	2.36–3.77
Long GP wait time	322	6.8	270	11.42	142	13.21	2.17	1.70–2.76	2.31	1.70–3.15
GP after hours	37	0.78	26	1.10	20	1.86	1.45	0.67–3.12	1.84	0.83–4.04
Shortage of GPs in the area	52	1.10	66	2.79	58	2.15	3.31	1.93–5.68	5.40	3.27–8.92
No bulk billing	5	0.11	7	0.3	1	0.09	2.87	0.62–13.32	0.36	0.04–3.56
Difficulty accessing specialist	92	1.94	105	4.44	78	7.26	3.08	1.98–4.76	4.69	2.91–7.56
Dental wait time	21	0.44	22	0.93	9	0.84	2.21	1.00–4.88	2.87	0.77–10.68
Shortage of health services	75	1.58	95	4.02	51	4.74	2.58	1.66–4.00	3.00	1.75–5.14
ED wait time	58	1.22	29	1.23	12	1.12	1.06	0.55–2.04	0.59	0.22–1.57
Quality of treatment	80	1.69	59	2.49	26	2.42	1.53	0.96–2.44	1.54	0.85–2.78
Elective surgery wait time	3	0.06	4	0.17	4	0.37	2.34	0.32–17.30	28.23	3.97–215.26
Cost of healthcare services	57	1.2	48	2.03	9	0.84	1.86	1.11–3.12	0.57	0.24–1.37
Transport issues	39	0.82	47	1.99	74	6.88	3.45	1.72–6.92	11.38	6.25–20.72
Other difficulties	136	2.87	110	4.65	68	6.33	1.51	1.06–2.15	2.87	1.91–4.32

Data from the NSWCPHS 2011–14. Totals calculated using probability weights calculated by the CEE, NSW Ministry of Health

It is also noteworthy that despite the paucity of GPs in communities of various sizes in Western NSW that is shown in Tables 13–16, only 2.8% of Inner Regional and 2.2% of ROS respondents to the survey reported a lack of GPs in the area. This apparent under-reporting of an evident lack of a service suggests that rural families regard having to travel out of their area to access healthcare for their child as a normal phenomenon that they just have to put up with. This stoicism in the face of a clear disadvantage in the distribution of healthcare services mirrors the discrepancy between the clear rural/urban inequality in healthcare outcomes described in Chapter 1, and the low level of expressed dissatisfaction with healthcare services described below (section 5.5).

Few respondents in urban and rural areas reported lack of bulk-billing practitioners or inability to access GP services after hours and these problems were not more likely to be problematic for those families than for urban families (see Table 18 and Figure 7), although lack of an after-hours GP service is definitely a problem for some families, as one of the interviewed parents explained (see below). The report of findings from the 2016 Survey of Health Care (of adult Australians) conducted by the AIHW and the ABS, reported that 20% of rural adults (compared with 3% of urban adults) stated that not having a specialist nearby made it less likely that they would see one (380). These findings of a survey of adults cannot be directly extrapolated to parents of children, because parents are likely to be more solicitous of their children's health than they are of their own(381, 382). The 2016 Survey of Health Care also found, however, that rural people were more likely than urban people to have visited an ED in the last 12 months because no GP was available when they needed one (380). A parent from Inner Regional NSW mentioned this reliance on hospital emergency department services after hours:

> … *during a Friday, Saturday, Sunday night, if you have a child who's sick, your only option is to drive to a hospital. You don't have a local GP or anyone on call, you can go to the ambulance if it's life threatening but usually you have to drive in if you have a sick child to a hospital situation to have them checked if it's not life threatening, or you wait.* Parent C: Inner Regional

5.4 Problems with health services in general

Only 1.6% of urban respondents to the NSWCPHS reported a shortage of healthcare services in general, but the lack of services relevant to the healthcare of children, especially in less populous rural localities (as shown in Tables 13-16), was more likely to be reported as a barrier to healthcare access by respondents in rural NSW (4.0% of Inner Regional

respondents: OR 2.6, 95%CI 1.66–4.00 and 4.7% of ROS respondents: OR 3.0, 95%CI 1.75–5.14) (Table 18 and Figure 7), as described by a parent from inner regional NSW during interview:

> *…. In Sydney … I had a local mothers' group and it was really close to me and it was accessible. They were really really useful and helpful. They'd come and see you at the house whereas in the country you have one health nurse who you've got to book an appointment with three weeks in advance and she only comes once every two weeks. Sometimes she doesn't come at all. And when you've got a baby it's nice to be able to see a lady more often than once a month sort of thing to see what you're getting into*. Parent C: Inner Regional

Although paucity of healthcare services was more likely to be a problem for rural parents, they were not more likely to report poor quality of healthcare services overall than were urban parents, and although Inner Regional parents were more likely than to report that cost of services was a barrier to access, only 2% of Inner Regional parents reported that this was so, and ROS parents were slightly *less* likely than urban parents to report that service cost was a barrier to access (OR 0.6, 95%CI 0.24–1.37).

5.5 Problems of distance to services

Difficulty in obtaining transport to healthcare services was reported as a barrier to service access by only 0.8% of urban parents, but as one might expect, transport difficulties were increasingly reported by rural parents as their distance from major centres increased (see Table 18). It can be seen in Figure 2 that there are large areas of rural NSW that are well beyond walking distance to healthcare resources, and that access to those resources from those areas would require access to public transport or to a private car. A parent from Inner Regional NSW described the feeling of insecurity due to the distance to health services in this way:

> *… you do sometimes feel isolated if you're unsure and you have a new baby and you're up here and it's Friday night or Saturday night or Sunday night. And things with kids always seem to happen on Sunday nights for some reason.* Parent C: Inner Regional

Rosier and McDonald (2011) pointed out that young people, families with young children and single parents were among the subgroups of the population most likely to experience

disadvantage in access to transport, and that people in rural and remote Australia were especially likely to experience it (383). An Inner Regional parent recounted her experiences of travelling between small rural centres to obtain healthcare for her child:

> …..*I drove to* [small town] *to have her checked on a Sunday because it was the only* [ED] *open, the closest one open I should say, and then because they don't have any way of observing any one over night or in a long time period then they had to send us on to* [larger town], *which is a nightmare for us because it's two hours in the opposite direction*. Parent C: Inner Regional

Rosier and McDonald noted that low levels of public transport coverage were common in rural and remote areas, especially those where the population is sparsely distributed, and that while governments and the population generally assume that this low extent of coverage is satisfactory and that every household will have access to a private vehicle, some remote areas of Australia have low levels of private vehicle ownership (383, 384). Nutley (2003) found that 6.7% of households in rural south eastern Australia had no private car, while 38% had only one car (384), which may be unavailable to transport a child to a healthcare appointment if a family breadwinner needs it for transport to work.

Fritze's (2007) study of the transport experiences of 45 young mothers in regional and urban Victoria found that 56% had difficulty in attending medical appointments (including those for their children) because of transport difficulties. Half of that cohort did not have a car, and a third of those whose family did own a car had only limited access to it (385). In those areas with public transport services (such as regional towns or areas between neighbouring towns), parents reported difficulties getting prams on and off buses, that drivers often failed to help, and/or bus company regulations required prams to be folded before boarding the bus. Further, some of the mothers interviewed stated that these difficulties discouraged them from using bus services at all (385). In the case of a mother taking a child to a healthcare appointment, this would mean the child missing the appointment. Children with a disability, for example those in wheelchairs, have particular difficulty entering and leaving public transport (383), and so are acutely dependent on the availability of private transport or on taxis, which may be prohibitively expensive, even when the child receives (Australian) National Disability Insurance Scheme funding.

5.6 Problems in gaining access to specialists

Transport difficulties may also partly explain rural NSWCPHS respondents' problems in gaining access to specialists (Table 18 and Figure 7). While only 1.9% of urban respondents reported difficulty in access to specialists, 4.4% of Inner Regional respondents and 7.3% of ROS respondents reported such difficulties (see Table 18). Children can need access to a range of specialists, from general paediatricians to sub-specialty paediatricians such as respiratory or cardiology specialists, as well as dermatologists, ophthalmologists and paediatric surgeons. As pointed out in section 1.11, some paediatricians are permanently located in towns such as Dubbo and Orange but some sub-specialists visit these and other towns at intervals of a fortnight or a month, while some paediatric sub-specialists are only found in the urban centres of Sydney and Newcastle. Long waiting times may be a problem for visits to specialists in regional towns, because their small numbers mean that each serves a large patient population. Consultations with visiting specialists mean obtaining transport to the clinic in the regional centre at the exact time and date of the specialist's fortnightly or monthly visit, and public or private means of transport may not always be available to meet that appointment. An appointment in a distant centre – whether Sydney, Newcastle or a regional centre which is far from the family's residence – requires long-distance transport, either private or public and sometimes an overnight stay. Costs of transport and accommodation, the need for a parent to have time off work, and the availability of transport can all make a visit to a far-off specialist problematic for a rural family. This disruption to education and to family life caused by accessing centralised specialist care was described by a parent from outer regional NSW:

> *There's usually a half day off school here* [to attend an appointment with the specialist in the regional town]. Parent B: Outer Regional

As noted above, difficulty in accessing specialists was only reported by a small proportion of respondents (7.3% of 1075 ROS respondents). Nonetheless, for those respondents (who may be those without ready access to transport), it *was* a serious problem. As pointed out in section 5.1, the 2016 Survey of Health Care (of adult Australians) found that 58% of rural adults (compared with 6% of urban adults) stated that not having a specialist nearby made it less likely that they would see one (380). These findings cannot be directly extrapolated to the situation of children, but the lack of specialists nearby does constitute a barrier to access to them. The role of coordination of services and their modification to meet the needs of

individual patients with appointments to clinics far from home is discussed in sections 6.6 and 8.3.

5.7 Problems with hospital emergency departments

Respondents to the NSWCPHS were asked to rate their child's last visit (if there had been one) to each of eight types of healthcare service on a five-point scale from *excellent* to *poor* (see section 4.7). Table 19 shows the number and percentage of respondents (using probability weights calculated by the CEE) who assessed the last visit to a health service with their child as *fair* or *poor*. The first three pairs of columns show the numbers and percentage of respondents who assessed their child's last visit to the service as *fair* or *poor*. The second-last pair of columns show the ratio of the odds of Inner Regional families describing the last visit to a service as *fair* or *poor* to the odds of urban families doing so and the 95%CI around that estimated OR. The last pair of columns shows the same information for ROS compared with urban respondents. Highlighted data show the service for which the 95%CI around the OR excludes the value 1.0. Figure 8 shows the same information in graphical form. The vertical line in Figure 8 represents the OR of 1.0. The figure shows that only in the case of Inner Regional EDs can one be 95% confident that the true OR of rural parents reporting dissatisfaction with the service to that of urban parents was greater than 1.0. While the estimated OR in the cases of ROS Community health centres and community dental services was greater than 1.0, the 95%CIs were wide, possibly due to the small number of respondents, so that less credence should be placed in these estimates of OR.

For most services, as Table 19 and Figure 8 show, rural parents were no more likely than urban parents to report dissatisfaction with the services provided. The exceptions were visits to rural EDs, where, while 2.6% of urban parents rated their child's last visit to an ED as *fair* or *poor*, 4.1% of parents from Inner Regional areas rated their child's last ED visit as *fair* or *poor*, as did 4.3% of ROS parents. Table 19 and Figure 8 also show that the child's last visit to a community health centre or a community dental service was more likely to be rated fair or poor by a ROS parent than by an urban parent.

To explain why families rated health services as *fair* or *poor*, they were asked to describe specific problems with health services. Table 20 and Figure 9 show these problems reported for ED visits – the service which was more likely to be reported as *fair* or *poor* by Inner Regional parents than by urban parents. In Table 20, the first three pairs of columns show the numbers and percentage of respondents who gave each reason for assessing their child's last ED visit as *fair* or *poor*. The second-last pair of columns show the ratio of the odds

of Inner Regional families reporting that problem to the odds of urban families doing so and the 95%CI around that OR. The last pair of columns shows the same information for ROS and urban respondents. Highlighted data (Table 20) show the problems in the ED that were more likely to be reported by rural than by urban respondents (the 95%CI around the OR excludes the value 1.0). Table 20 shows that the absolute numbers of parents who reported each category of problems as a reason for giving a low rating to their child's last ED visit was small. This means that the findings are susceptible to undue influence by individual reports which may not be representative of what would be found if all parents in rural NSW were surveyed. The small numbers reporting each ED problem also explains the wide confidence intervals around ORs seen in Figure 9, which for similar reasons, mean that less credence should be placed in estimated ORs with very wide 95%CIs, such as communication problems in the ED or no treatment or follow-up, reported by parents in Inner Regional areas. Nonetheless, the fact that some parents reported these issues, means that they could indeed be problems for rural parents and should be further studied, with the aim of improving services for rural children and their families. During interviews, parents from outer regional NSW described this kind of communication problem:

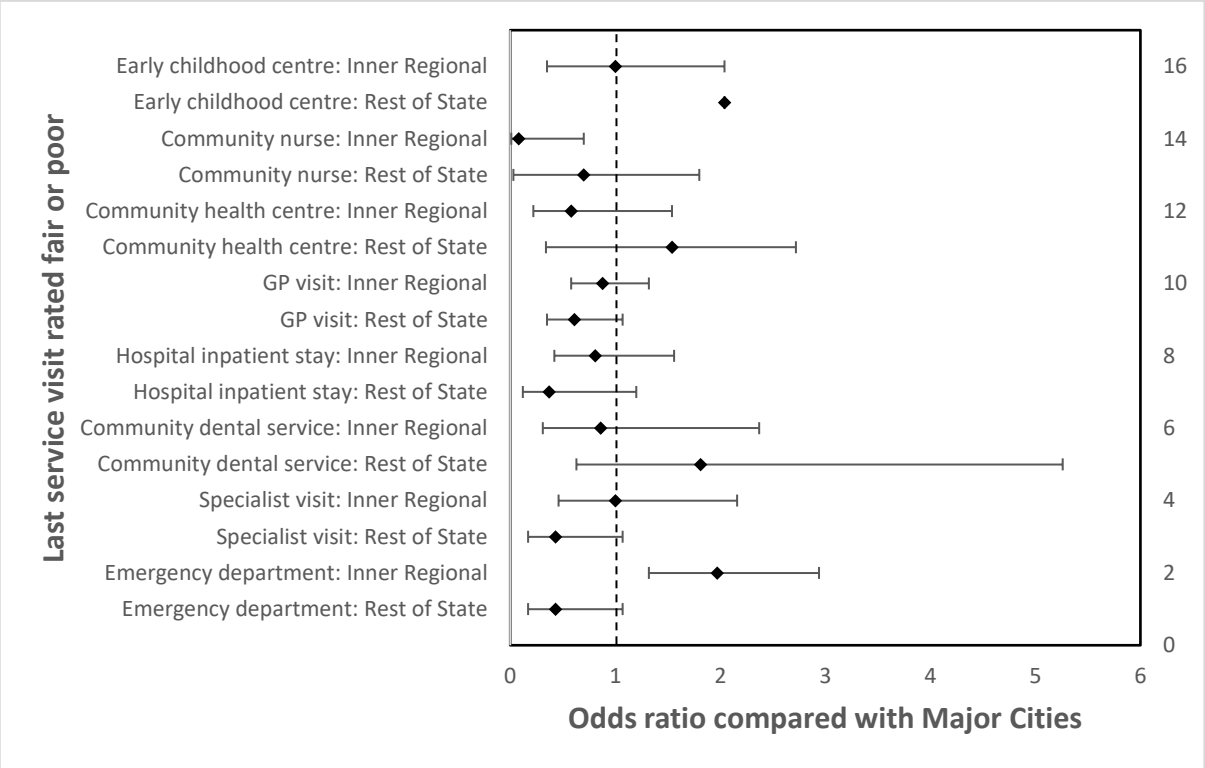
> [During an acute presentation to the local hospital] … *we're asking questions and we just aren't annoying the doctors because we're worried but we're actually trying to get an understanding so we'll be able to do more next time. We sort of got given a bit of a "oh these are the annoying parents, go away" sort of thing …*
>
> [Later, during the same presentation when the doctor at the local hospital consulted the regional paediatric service] *… but the doctor was trying to talk to the nutritionist and the registrar and they wouldn't let me be part of the conversation, they shut the door on me.* Parents A: Outer Regional

A separate reason for careful interpretation of some of the findings in Table 20 was pointed out by Coulter (2006) and Rao et al. (2006) with reference to patient satisfaction surveys in the UK (386, 387). Rao et al. found little relationship between patients' assessments of the clinical competence of their GP and objective findings on review of those patients' records (387). Coulter pointed out that patients' assessments alone are not a reliable way of assessing competence, but may be more useful if combined with other information such as records of prescribing or vaccination practice, and could be used in ongoing practitioner education programs (386).

TABLE 19 SUMMARY STATISTICS OF PARENTS ASSESSING THEIR CHILD'S LAST VISIT TO A RANGE OF HEALTH SERVICES AS FAIR OR POOR, BY LEVEL OF REMOTENESS AND ODDS RATIO (WITH 95%CIS AROUND ORS) OF IR AND ROS PARENTS COMPARED WITH MC PARENTS

Assessment of last visit to a health service as fair or poor	**Major Cities** N = 4736		**Inner Regional** N = 2365		**Rest of State** N = 1075		**Inner Regional**		**Rest of State**	
	n	% Yes response	n	% Yes response	n	% Yes response	Odds ratio	95%CI	Odds ratio	95%CI
Early childhood centre	18	0.38	6	0.25	0	0	1	0.35–2.04	empty	empty
Community nurse	11	0.23	1	0.04	1	0.09	0.08	0.01–0.70	0.21	0.03–1.80
Community health centre	21	0.44	8	0.34	8	0.74	0.58	0.22–1.54	0.96	0.34–2.72
GP	136	2.87	67	2.83	31	2.88	0.88	0.58–1.32	0.61	0.35–1.07
Hospital inpatient admission	37	0.78	20	0.85	7	0.65	0.81	0.42–1.56	0.37	0.12–1.20
Public dental clinic	15	0.32	9	0.38	9	0.84	0.86	0.31–2.37	1.81	0.63–5.26
Specialist	44	0.93	22	0.93	9	0.84	1	0.46–2.16	0.43	0.17–1.07
Emergency department	125	2.64	96	4.06	46	4.28	1.97	1.32–2.94	1.5	0.91–2.45

FIGURE 8 ODDS RATIOS (WITH 95%CIS) OF PARENTS FROM RURAL AREAS (IR OR ROS) COMPARED WITH MC PARENTS, DESCRIBING THEIR EXPERIENCE AT THEIR CHILD'S LAST VISIT TO A HEALTH SERVICE AS *FAIR* OR *POOR*



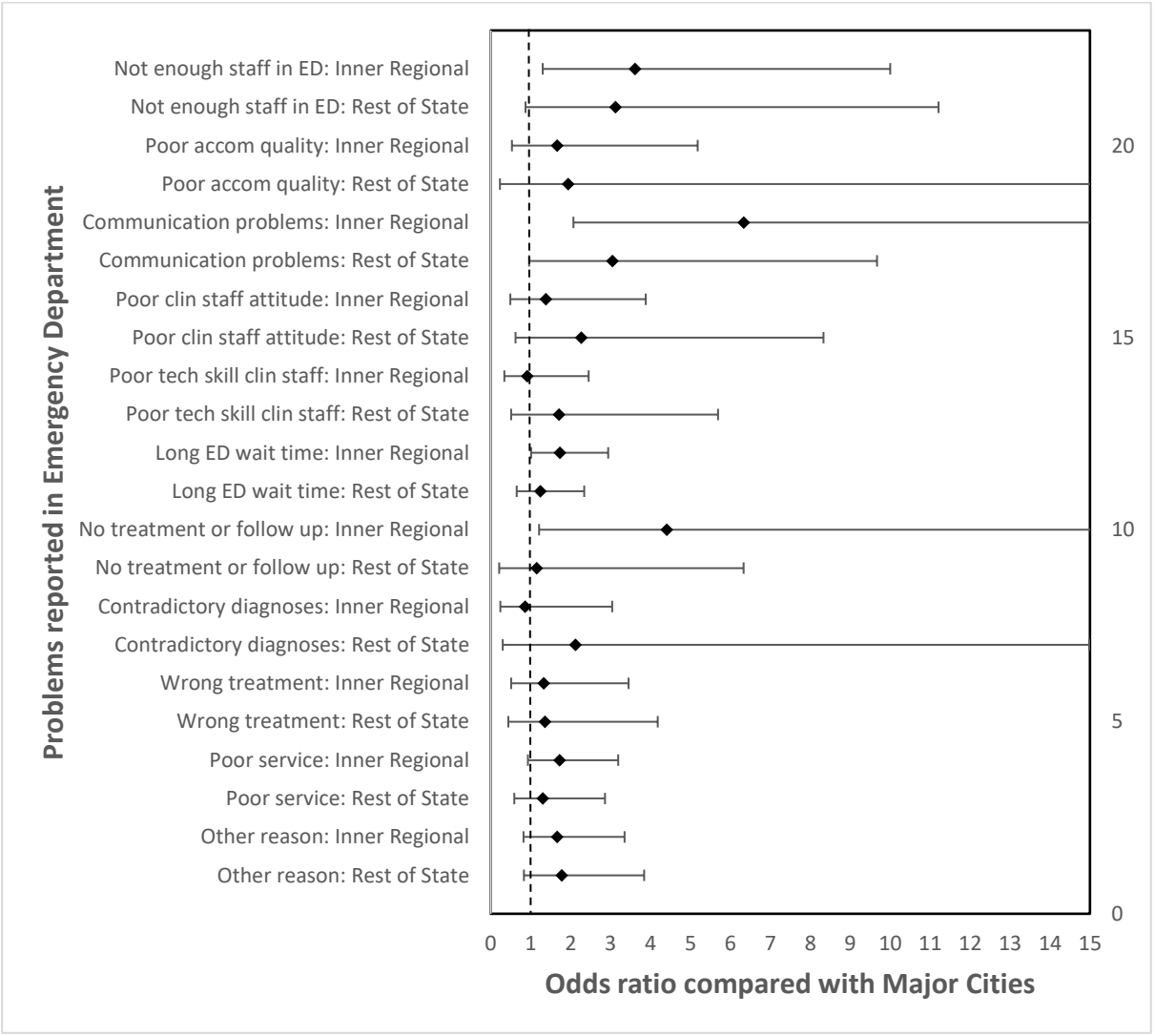
Data from NSWCPHS 2011–14. N = 8176.

TABLE 20 SUMMARY STATISTICS OF PROBLEMS WITH THEIR CHILD'S LAST EMERGENCY DEPARTMENT VISIT, BY LEVEL OF REMOTENESS, REPORTED BY PARENTS FROM IR AND ROS, SHOWING ODDS RATIOS (AND 95%CIS) COMPARED WITH MC PARENTS

What ED problems were reported?	Major Cities n = 4736		Inner Regional n = 2365		Rest of State n = 1075		Inner Regional		Rest of State	
	n	% Yes response	n	% Yes response	n	% Yes response	Odds ratio	95% C.I.	Odds ratio	95% C.I.
Not enough staff in ED	15	0.032	10	0.42	5	0.47	3.61	1.30 to 10.00	3.12	0.87 to 11.21
Poor accom quality	9	0.19	8	0.34	1	0.09	1.66	0.53 to 5.18	1.94	0.23 to 16.18
Communication problems	9	0.19	11	0.47	7	0.65	6.33	2.07 to 18.34	3.05	0.96 to 9.67
Poor clinical staff attitude	15	0.32	13	0.55	7	0.65	1.38	0.49 to 3.88	2.27	0.62 to 8.33
Poor tech skill clinical staff	14	0.3	7	0.3	6	0.56	0.911	0.34 to 2.45	1.71	0.51 to 5.69
Long ED wait time	79	1.67	53	2.24	26	2.42	1.73	1.01 to 2.94	1.24	0.65 to 2.34
No treatment or follow up	8	0.17	8	0.34	3	0.28	4.41	1.21 to 16.07	1.15	0.21 to 6.33
Contradictory diagnoses	11	0.23	5	0.21	2	0.19	0.86	0.24 to 3.04	2.12	0.30 to 14.98
Wrong treatment	20	0.42	11	0.47	6	0.56	1.33	0.51 to 3.45	1.36	0.44 to 4.18
Poor service	47	0.99	35	1.48	19	1.77	1.72	0.93 to 3.19	1.3	0.59 to 2.86
Other reason	51	1.08	22	0.93	17	1.58	1.66	0.82 to 3.35	1.78	0.83 to 3.84

Data calculated from NSWCPHS 2011–14 using probability weights calculated by the CEE, NSW Ministry of Health

FIGURE 9 ODDS RATIO WITH 95% CONFIDENCE INTERVAL, OF PARENTS FROM RURAL AREAS (IR OR ROS) COMPARED WITH MC PARENTS, GIVING A REASON FOR DESCRIBING THEIR CHILD'S LAST EMERGENCY DEPARTMENT VISIT AS FAIR OR POOR



Data from NSWCPHS 2011-2014.

5.8 How useful are patient experience surveys in assessing healthcare?

In the last 10 years, it has become increasingly accepted among healthcare managers in Australia and other countries that the "Triple Aim" is the appropriate goal of healthcare and of healthcare systems (388). The Triple Aim consists of three parts: improving the healthcare experience of individuals, improving the health of the population, and reducing the cost per capita of healthcare (389). While other types of patient survey can assess changes in the health status of individual patients and can assess direct and indirect monetary costs to individual patients of accessing healthcare, the main roles of patient experience surveys are to examine the ways in which groups of patients (or their surrogates, in the case of child patients) experience their contact with various aspects of the healthcare system and to assess subsidiary aims of a healthcare system, such as individuals' experience of the *coordination* of healthcare. For example, the AIHW uses the 2016 Survey of Health Care in its Coordination of Health Care Study (380, 390), of which the first results, referring to rural adults, appeared in 2018.

Donabedian (1972) proposed that a healthcare system should be organised such that consumers (potential patients), healthcare providers and managers have equal power in directing the activities of the system (391). This implies a major role for ongoing review of patient experience and evaluation (however this is organised) of healthcare in directing the planning and activity of the healthcare system. It is claimed that "satisfaction is an important outcome measure" (392) and "patient feedback can be used systematically to choose between alternative methods of organising or providing healthcare" (392), and "Measuring coordination of care from a patient's perspective is a crucial step in identifying common themes, areas for improvement and monitoring the impact of change" (380). However, a study of the use of patient survey data from Victorian hospitals over five years found that many hospitals had made little or no use of the data that they had collected to inform change (393). Among those hospitals which had responded to the survey data, the changes made were most commonly in the areas of catering, the physical environment and communication, rather than in areas more relevant to the delivery of healthcare (393).

The responses to patient satisfaction surveys are necessarily subjective and the findings prone to self-selection bias (394), especially when response rates are low. Some larger and more frequently used survey instruments – such as the Patient Satisfaction Questionnaire, based on a large reference database (395, 396) – have demonstrated validity and reliability, but offer no opportunity to include questions relevant to an individual healthcare system such as NSW Health (395, 396). This means that there is often a trade-off between validity and reliability on the one hand

and relevance on the other. Patient satisfaction with healthcare has multiple dimensions, which Fitzpatrick (1991) listed as rapport, cost (direct and indirect) to the patient, communication, physical environment, technical competence, health outcome, organisation, continuity of care and follow-up, access, inclusion of psychosocial care, and quality of care overall (392). Direct costs include clinic or provider charges and transport costs, while indirect costs might include costs of childcare for siblings or wages foregone.

Hall and Dornan (1988) examined 107 published patient satisfaction studies and found that access was only ranked seventh in the frequency with which it was measured, while health outcome was ranked tenth. They found that in overall contribution to self-reported satisfaction of patients, outcome was only ranked fourth, while access was ranked seventh (397). Donabedian's analysis of the quality of healthcare distinguished three components: structure (the environment in which care is provided), process (the method by which care is provided) and outcome (of healthcare) (391, 398). A study from Utrecht examined the importance of Donabedian's components to an overall assessment of healthcare, made by adult patients who had been treated for a variety of medical and surgical conditions. Its authors found that process explained most of the variance in the global score given by respondents, followed by structure, while health outcome only explained 5–13% of the variance in the global score (398).

To make a useful contribution, either to modifying the function of a health service, or (as in the present case) to comparison of the healthcare experiences of two or more groups in the community, a survey must ask precise questions about specific events which involve aspects of healthcare (392), for example "during your last GP visit, was your blood pressure measured?" This is to minimise the differences in interpretation and in importance which individual respondents to a survey place on aspects of care such as the technical skill of clinicians, communication difficulties or "poor staff attitude". The inclusion of these topics in the NSWCPHS makes these questions less useful for inter-group comparison, although they give general information about the congruity between patients' (i.e. parents') expectations of the service and what the service actually offers.

5.9 Limitations of this part of the study

The 95%CIs around ORs for some survey questions were very wide (see section 4.7 above), making the results of rural/urban comparisons for those questions less reliable (see Tables 18, 19 and 20 and Figures 7 to 9).

5.10 In summary

This chapter described the results of analysis of patient experience data from the NSWCPHS from the years 2011 to 2014. The data illustrate the experiences of families in accessing, for their children, healthcare resources allocated to geographical areas of NSW by elected (i.e. health ministers) or non-elected (i.e. Health Department bureaucrats) officials of the Australian or NSW Health Departments. The NSWCPHS findings were further illustrated by data from four interviews with parents of rural children. Rural families who responded to this survey were more likely to report difficulties in accessing healthcare for their child, and families in areas more remote from major population centres were more likely to report such difficulties than those living closer to major centres. In particular, rural families were more likely to report difficulties with GP services and with EDs than urban families, and rural families were more likely to have experienced transport difficulties and difficulty in accessing specialist services.

Finally, the chapter examined the role of patient experience surveys in the assessment of healthcare, pointing out the subjective nature of such surveys and the need to focus the survey's questions on answering particular questions which will be useful in formulating or adjusting specific health policies. The next chapter describes findings from interviews with officials involved in making decisions about the allocation of healthcare resources that are needed by rural children.

Chapter 6: Findings from interviews with healthcare decision-makers

The previous chapter describes the geographic location of healthcare resources for children in Western NSW and the experiences of NSW parents in accessing healthcare for their child, based on analysis of the results of the NSWCPHS 2011–14. In that chapter, the experiences of rural parents are compared with those of urban parents. Many of the urban–rural differences in access to healthcare resources are due to decisions made by government departments about what healthcare resources and programs will be made available to Australian children, and where they will be located. As described in section 2.5, those healthcare RA decisions are made ultimately by state or federal parliaments, based on advice from the cabinet. Advice to cabinet is given by officials of the relevant health department and in some cases, by external advisers.

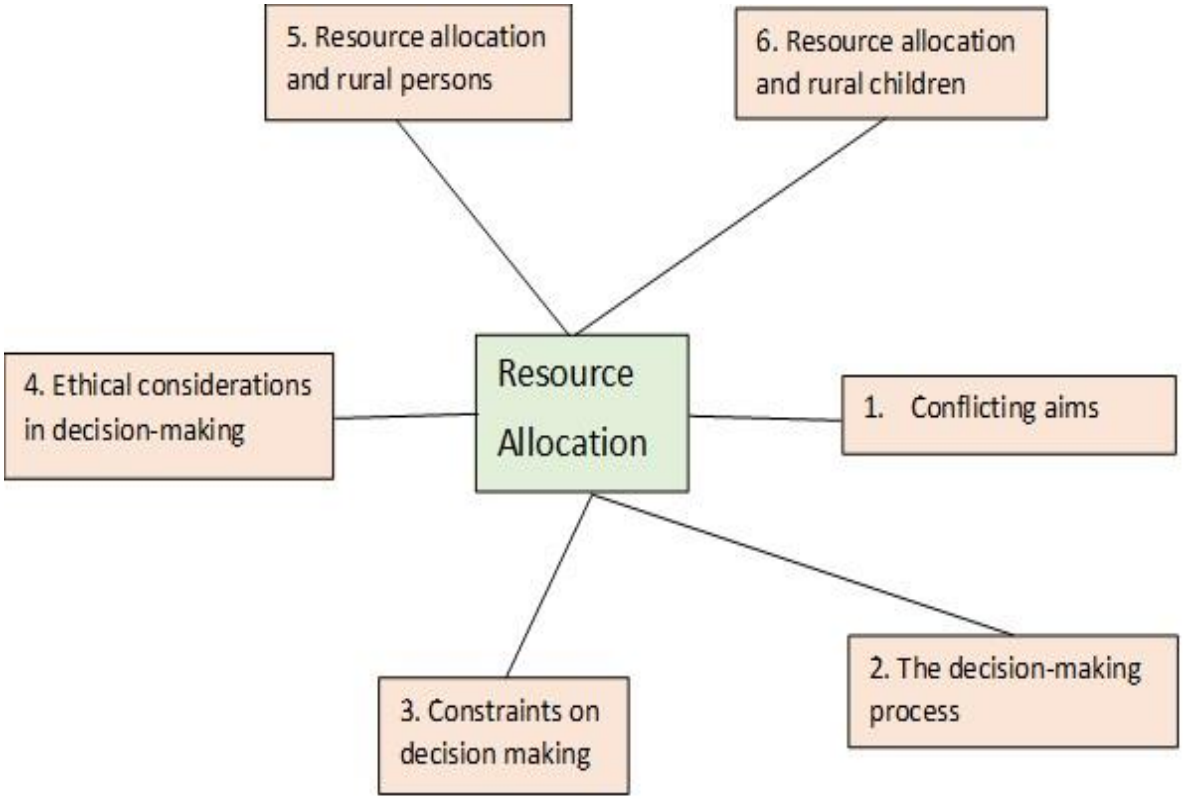
This chapter describes findings of analysis of interviews with officials and advisers of the Australian and NSW Departments of Health, of whom some were elected (i.e. politicians) while others were non-elected (i.e. bureaucrats). As noted in Table 12, four officials of the Australian Federal Department of Health and Ageing were interviewed, two individually and two others together. Three officials of the relevant LHDs were interviewed by telephone. A former state Health Minister was interviewed by telephone and a Parliamentary Secretary for Health was interviewed face-to-face. Two advisers to the NSW and Federal Health Departments were interviewed together (by telephone). Altogether, 11 healthcare decision-makers or advisers to decision-makers were interviewed. The average duration of interview was 51 minutes. In order to preserve the anonymity of the interview participants, they are identified here only as advisers or officials, but not as elected or non-elected, or as federal or state. The processes of interview and of analysis of the data are described in sections 4.14 and 4.15.

After examination of the initial codes and the original data, the data were re-coded and the codes grouped into 10 categories (Co-ordination; Inputs into the decision; Rurality; The decision-makers; Ethical considerations; Methods of decision-making; Childhood; Non-health considerations; Outcome and effects of the decision; Priorities). The codes and categories were stored in an Excel file. The purpose of this arrangement under headings was to facilitate manipulation of the data and establishment of logical connections between the various topic areas. The codes were then re-examined and re-grouped into seven new categories (What is decided; Aims of decision-making; How decisions are made; Influences on decision-making; Constraints on decision-making; Decision-making and rurality; Decision-making and childhood.) Some codes appeared in more than one

category. Themes were identified, either as topic areas which emerged from the interviews and which appeared to be important to understanding aspects of the process of healthcare RA decision-making and its ethical dimensions, or as topic areas which appeared to gather together common threads in the discussions with several interviewees.

During the interviews, participants discussed the overall topic of making decisions about the allocation of healthcare resources that are relevant to rural children. Six main themes emerged from the discussions: the decision-making process; conflicting aims; constraints; ethical principles in decision-making; RA and rural people; RA and children. These main themes, which emerged from examination of the interview transcripts, are shown in Figure 10. Within each of these main themes, sub-themes emerged, which are discussed in detail below. In addition, a map was prepared of each theme and of its sub-themes (e.g. Figure 11).

FIGURE 10 THEMES OF RESOURCE ALLOCATION



The division of the data into themes and sub-themes is to some extent artificial, in that aspects of several sub-themes cross the boundaries between major themes. For example, the sub-theme of political constraints on decision-making is a sub-theme of the conflicting aims of decision-making, but is also a sub-theme of the major theme of constraints and of the major theme of the decision-making process. Similarly, financial considerations are a sub-theme of constraints and of the major theme of the role of ethics in decision-making.

Before considering the ethical framework which guides healthcare RA decisions, it is first necessary to address the question of who makes those decisions. Section 2.5 describes the formal arrangements for the allocation of financial resources by state and federal governments in Australia, and notes that the ultimate power to allocate funds to a healthcare program lies with the parliament of each jurisdiction, advised by its executive.

6.1 Who makes decisions about the allocation of healthcare resources?

This is a question about the power to fund healthcare programs and about the advice given to the parliament to enact those decisions. The decision-makers are:

- Politicians
    - Federal
    - State
- Bureaucrats
    - Federal
    - State head office
    - Local Health District
- Advisers to health departments

All of the officials (both elected and non-elected) who were interviewed, agreed that there is a hierarchy of power to make RA decisions and that most decision-making power rested in the hands of politicians. The next section discusses the roles of politicians, of health department bureaucrats and of LHD bureaucrats in the allocation of healthcare resources. It also discusses the influences and constraints on each group in fulfilling their role in healthcare RA.

While the hierarchy of decision-making power appears to exist (according to the accounts of the interviewees) at both federal and state government levels, the role of the Australian Federal Government in the allocation of healthcare resources differs from that of the state governments in a way that is relevant to one of the research questions of this thesis: in particular, the nature of the ethical framework which underpins the allocation of healthcare resources now. The Federal Government sees its role as an allocator of blocks of funds to services or to groups in the community, but not as the organiser or coordinator of the exact way in which those funds are used for the benefit of individual members of the community. This Federal Government concern with the *overall* health of the community or of large segments of the community (e.g. all patients with diabetes, or all people in some defined age group) is a consequentialist concern (see section 7.2),

and carries the disadvantages common to consequentialist principles for some individuals in the community concerned. This broad-brush approach of the Federal Health Department to allocation of resources was expressed by one official in this way:

> *The Federal government in particular delegates much of the decision-making around the needs of individuals to regional authorities. This means that prioritising individual care versus majority care is not generally a function of the Federal government*. Official 6

This reflects the view, expressed by another official, that the proper role of the Federal Government is to provide funding for services rather than the details of individual services or their coordination with other state, federal or local government functions or with privately provided services.

The role of cabinet and of health ministers in decision-making

As section 2.5 describes, at federal and state levels of government in Australia, recommendations on program funding are submitted by cabinet for ratification by the parliament. Discussion within cabinet of these recommendations is led by the relevant minister, briefed by her or his departmental officials. The interviewees agreed that elected officials (state or federal Ministers for Health) had the greatest decision-making power about which healthcare programs would be funded.

> … at the end of the day *it's his* [the minister's] *decision with his department about where those funds will actually go.* Official 3

Many of the influences (discussed in sections 6.4 and 6.5 below) on these decisions are funnelled through the person of the minister (or, before a change in the governing political party, the shadow minister) who then has the power to decide on what recommendations to make to cabinet or to shadow cabinet about healthcare RAs. There was agreement among the interviewees that at federal level, individual ministers have limited ability to reallocate funds from one program to another, though at state level, ministers appear to have a greater ability to reallocate funds, though the total departmental funding allocation is fixed.

Although the power relationships within cabinet may vary from one government to another, in at least some cabinets, as one interviewee pointed out, the leader of the government (the prime minister in the case of federal parliament, and the premier in the case of a state parliament) has more decision-making power than other cabinet members.

> *… we have a number of priorities that are already set by our premier.* Official 3

For both federal and state politicians, the need to restrict overall funding so as to remain within the Department's funding allocation is a very major priority. This means that the cost of individual

healthcare programs and parts of programs is a significant factor determining their adoption or non-adoption. Similarly, for both federal and state politicians (especially for ministers and state premiers), several interviewees pointed out that healthcare RAs which were likely to attract votes at the next election were more likely to be enacted. In a particular electorate, the construction or renovation of, or addition to, a healthcare facility was more likely to gain votes than some less tangible healthcare modality. For the same reason, one-off funding allocations have more visible results than ongoing funding, so these tend to be more popular with politicians for electoral reasons. On the other hand, withdrawal of ongoing funding from a program is electorally unpopular and hence is difficult for a politician and for her or his advisers to undertake.

Apart from questions of whether a healthcare program will be adopted and funded, there is the issue of where the idea came from that a program *should* be adopted. In some cases, this comes from departmental officials, based on evidence of need, of usage or on other forms of evidence. In other cases though, the idea appears to originate with the minister or with a political adviser to the minister, based less on evidence of need for the program or evidence of its probable efficacy in achieving some healthcare outcome recognised as desirable, than on impressions, anecdote, advice from colleagues or on the electoral popularity of the program. The interviewed officials and healthcare advisers agreed that this was a common origin of programs. Further, it was agreed that as these ideas for programs originate high in the power hierarchy, the advice of expert officials lower in the power structure is often bypassed in the decision on whether to adopt such a program.

The role of bureaucrats in decision-making about resource allocation

The officials interviewed, then, agreed that ultimately, politicians – and especially members of cabinet – held the power to make decisions about the allocation of healthcare resources. Non-elected officials who were interviewed saw the role of bureaucrats as an advisory one: offering advice to guide decisions in a way which maintained the stability of healthcare programs in the face of changes in the political party of government and of changing political agendas.

> *The bureaucracy is in a sense the steward of the system, whose role is to carry out the legislative program of the government of the day, but also to maintain the long view, and to ensure the continuity of long-term programs*. Official 5

The non-elected officials emphasised, though, that their role was an advisory one rather than a decision-making one, despite the fact that an individual adviser must necessarily make a decision about what advice to offer. Those officials also emphasised that, at least at the level of allocation of financial resources, their power to make decisions was very limited. As one expressed it:

> *We don't have the ability usually, without the Minister's consent, to move money from one program to another … money is appropriated for a particular purpose, so the programs are the expressions of those purposes*. Official 7

Advisers to government (state and federal) expressed a less charitable view of this difference in decision-making power between politicians and departmental officials and of the nature of the advisory role of bureaucrats:

> … *public servants no longer give frank and fearless advice to government, they do what government tells them to do.* Adviser 2

Officials agreed though, that the interests and the political beliefs of the more powerful members of the hierarchy (the politicians) constrained the choices which could be made by the less powerful (the bureaucrats) about the nature of the advice they could give about RA decisions.

The role of Local Health District personnel in resource allocation

In NSW, many health service delivery functions are devolved to the fifteen LHDs. In the view of officials of the head office of NSW Health, this means that the LHDs have considerable scope for RA within their area of responsibility. A senior official described the view of other senior officials of the head office of NSW Health:

> … *a policy … which was about reform of the governance of the health system in NSW and it was about devolution, setting up local health districts and boards which would then have far greater responsibility to deliver, in terms of government policy, but … within their own area, tailored to be suitable to their own communities.* Official 2

Although the intention of devolution of responsibilities to LHDs in NSW is to adapt State Government policy and health resources to the requirements of the local population, interviewed LHD officials felt that their scope for making decisions about RA was very limited:

> *So … I think it probably tends to come from the head agency around shifting the priorities if you like. More than probably our level*. Official 8

The officials and advisers described a structure within each health department, which is based on sub-units, each of which has a defined function. This sub-unit structure is most visible in the head office of the department, located in the state capital (in the case of state health departments) or in Canberra in the case of the federal equivalent. It is there that most decisions about RA to programs are made, leaving little discretion for reallocation of funds between programs to officials acting at LHD level. Further, the structure organised by functional sub-units tends to lead, according to

advisers and officials interviewed, to the sub-units operating independently of each other, even when their roles intersect, and indeed when the functional outcomes of the work of each sub-unit depends on the work of other sub-units. Coordination of the functions of the sub-units appears to depend not only on those who work within the sub-units, but also on more senior officials who are responsible for the work of more than one sub-unit.

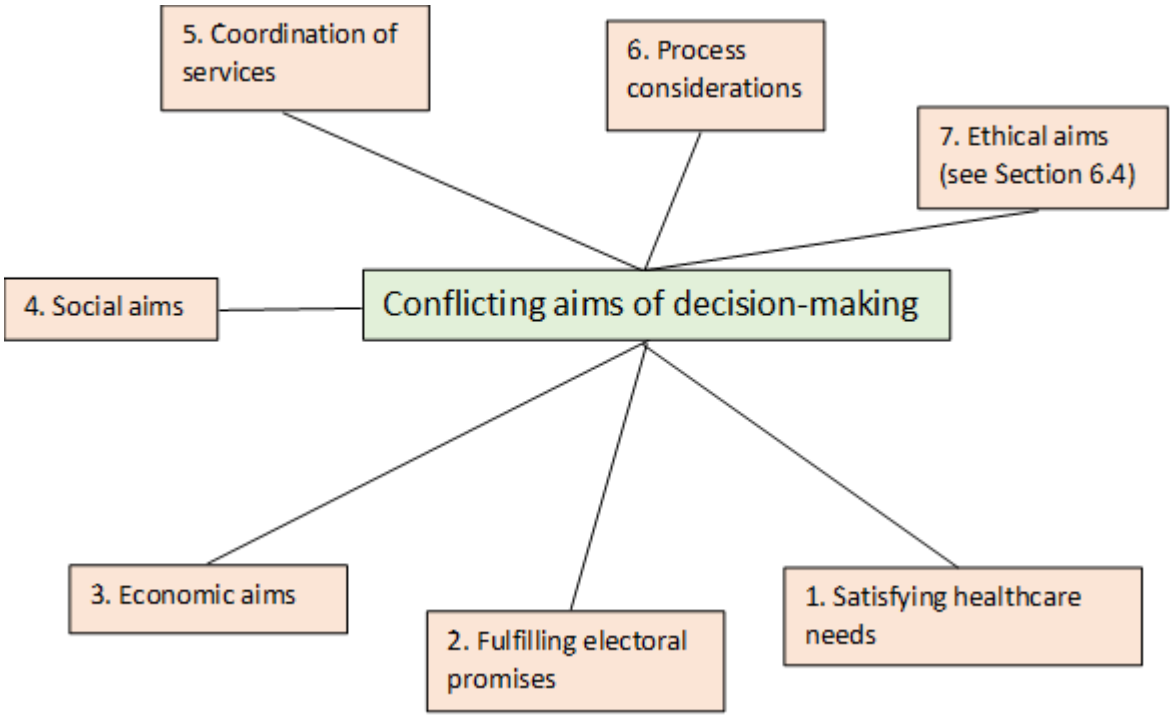
What emerged from these interviews with health department officials at various levels of seniority was a picture of a hierarchy of power to make RA decisions, at the apex of which is the premier (or prime minister, in the case of the Australian Parliament), followed by the minister for health, then, collectively, the other members of cabinet, then members of the bureaucracy, whose decision-making power was portrayed as limited to decisions about what advice to offer to those in upper levels of the hierarchy. Once the issue of who held the power to make RA decisions was settled, the first theme which arose from the interviews was: what was the fundamental aim of the officials in making decisions about how and where to allocate healthcare resources? What exactly were the decision-makers trying to do?

6.2 Conflicting aims of decision-making

Figure 11 shows the main theme of the conflicting aims of healthcare RA decision-making and the sub-themes within that main theme. The overall function of a health service depends on (among other things) the outcome of multiple decisions about the way in which financial, personnel and other resources are organised and distributed. The aim of individual decisions about allocation of resources, then, is related to the purpose of the healthcare system as a whole. Interview participants had a variety of perspectives on the purpose of the NSW and Australian health systems. Some officials felt that the role of government was to provide healthcare services to the public:

> … *obviously it's* (the government) *there to provide services, I think certainly in the health area, I think government absolutely has a role* … . Official 8

FIGURE 11 THE CONFLICTING AIMS OF HEALTHCARE RESOURCE ALLOCATION DECISION-MAKERS



Others however, emphasised the role of government in *facilitating* the provision of services rather than actual provision of services. There appeared to be a consensus among the officials that the role of a health department was primarily to ensure that something (healthcare services) was provided to the population. There appeared to be less emphasis on what the outcome of that service provision should be, although provision of services to satisfy needs for healthcare, mentioned by the last participant quoted, was a theme that emerged from many of the interviews. Exactly whose needs should be satisfied, and to what degree, when groups in the population compete for limited resources was not discussed as part of the aims of the service, and no officials mentioned the *coordination* of different health-related activities of a government as an aim of decision-making.

Satisfying healthcare needs as an aim of healthcare resource allocation

Participants were generally in agreement that healthcare resources should as far as possible be allocated in such a way as to satisfy a demonstrated need for healthcare. The principles of satisfaction of needs as a driver of RA decisions are described in Section 2.4. As noted in section 6.3 below, the identification of need, based on evidence, is the vital first step in the satisfaction of need. Clearly, satisfying *identified* healthcare needs of members of the community cannot be the only aim of RA, because data on actual needs are often incomplete. When total resources are limited, officials who make RA decisions must adjudicate between competing identified or presumed needs, and this

adjudication must be conducted according to some principle or principles other than simply that of satisfying needs. One official expressed the situation of RA when needs are uncertain in this way:

> … *we know who gets services, but we don't know the characteristics of people who don't, and in dental in particular, we have reason to suspect that the people who don't get services have a far greater need than the people who do because they have a lower income and dental health is directly correlated to income*. Official 1

Among children with a need which arises only intermittently (e.g. children with a traumatic brain injury who require rehabilitation appropriate to their developmental stage), who live in remote areas where population numbers are low, identifying and quantifying that need in a population is an especially acute problem. This can lead to a situation of incomplete or less than ideal satisfaction of the needs of some rural children. This problem was pointed out by an official:

> *For example, speech pathology for children in isolated areas is often handed over to adult speech pathology services, and speech-related issues for children in these services often appear less urgent than those of the larger population of adults, for example after a stroke or brain trauma*. Official 4

As well as satisfying an identified healthcare need in members of the population, RA decisions are often aimed at fulfilling a promise which the governing political party made to the electorate before being elected to govern.

Fulfilling electoral promises

Both elected and non-elected officials strongly expressed the view that a government was obliged to do the things (including the allocation of healthcare resources to particular population groups or in particular geographical areas) which it had promised to do in order to be elected to government. Indeed, several officials suggested that this was the *only* obligation of a government to the population on whose behalf it governs:

> *Yes, a government must make decisions which are consistent with its promises, even if the detail was not spelled out before the election.* Official 6

Others, though, felt that in addition to fulfilling electoral promises, a government should have a utilitarian aim in spending public funds to achieve the best overall health outcome for the population:

> [The duties of a government to its citizens are to] *do what they say they're going to do, be honest about it and I guess, not waste taxpayers' money. So, do things as efficiently ... you know, choose more efficient options against less efficient options.* Official 1

Economic aims of healthcare resource allocation decisions

Health department officials at federal and state level agreed that economic considerations always play a role in RA decisions, but felt that it was a background role rather than a primary role. The relevance of this is that provision of healthcare for a child living in a rural or remote area is considerably more expensive that provision of the same care to a child with the same illness who lives in an urban area. This means that as well as being an aim of healthcare RA decisions, economic considerations (of the best overall health outcome for the population that can be achieved with the financial resources available) also act as a constraint on what RA decisions can be made. One official described the twin aims of getting the best value for money in terms of overall health outcomes for the whole population, and doing what is possible:

> *Governments of both political persuasions are committed both to obtaining value for money and to as much child healthcare as it can afford*. Official 6

Although economic efficiency and effectiveness are aims of decision-making about the allocation of healthcare resources, economics is also a constraint on decision-making. Financial allocations must be made within a total departmental budget, which is itself determined by the cabinet of the relevant jurisdiction on the advice of its treasury. One official spelled out the aspects of that constraint:

> *When a decision is made to make a financial allocation to a healthcare program, the major economic considerations are total budget constraints and opportunity costs*. Official 5

Decision-makers' awareness of the need to restrain the apparently inexorable increase in per capita expenditure on health, described in section 2.2 and Table 12 above, was felt to be the link between economy as an *aim* of decision-making and as a *constraint* on decision-making. As one official put it:

> *In the broad* [view]*, value for money is important because it's around maintaining a sustainable health system.* Official 7

The officials interviewed were careful to avoid over-emphasising the role of economic considerations in RA decisions, despite the clear evidence of government guidelines in the form of the *Public Governance, Performance and Accountability Act 2013* (399) and the *Pharmaceutical Benefits Advisory Committee Guidelines* (400) on the requirement for economic criteria to be

satisfied in the allocation of funds, especially by Federal Government departments. One senior official expressed their view of the summarising role of economic evidence in decision-making in this way:

> *But economic evidence is not the only influence on* [resource allocation] *decisions. Most people* [i.e. most decision-makers] *are value-driven. Some are primarily utilitarian but others have other personal value frameworks*. Official 5

The officials emphasised that the overall budget of all health departments is limited and there is an underlying commitment to obtain the best value for money from that budget. On the other hand, some groups in the population have healthcare needs that are more expensive to satisfy than the average. For example, some illnesses require drugs or other forms of treatment that are very expensive. In these cases, there is an unstated limit on the amount of money that a government is willing to spend to keep an individual alive for a year. Despite that unstated but well-recognised limit, governments are willing to exceed it in payments for extremely expensive, potentially life-saving treatment for identifiable individuals. This example of the Rule of Rescue is discussed in section 7.7 below. Treatment for rural children with complex health needs, close to their home where the treatment is practically accessible, is very often expensive. Officials interviewed recognised that close-to-home care is an ideal, and one senior official stated that recognition specifically:

> *… but in terms of resource allocation we had to make sure that there was a fair distribution of funds so that those patients could be treated as close to home as possible in the best way possible*. Official 2

The conflict between, on one hand, that fairness in providing for rural children the close-to-home healthcare that is available to urban children, and on the other hand, the economic constraints which operate in the background of all RA decisions, was well recognised by most of the interviewees. As one said:

> *… it's going to cost a hundred and fifty thousand* [dollars] *to provide disability services for one year to one child living out there, but if they moved to somewhere bigger it would cost fifty thousand and if they moved into town, it would cost twenty thousand. I don't know how we resolve that*. Official 1

The role of equity in healthcare RA is discussed in sections 6.5 and 7.5 below. Interviewed officials of all levels of seniority and power in decision-making noted that the allocation of healthcare resources

has effects on individuals and communities other than its effects on health. These might be described as the social effects of RA, and in some cases, those social effects are an aim of RA.

Social aims of decisions about healthcare resource allocation

The survival of rural towns depends to some extent on the existence of government services such as hospitals, health centres, post offices, police stations, schools and government department offices. When those government facilities close, the population of the town declines and private businesses such as shops and equipment sales and repair businesses which depend on a critical mass of clientele become less viable (see Appendix 13). Senior officials recognised the importance of ensuring that decision-makers were aware of the role of location of government services in stabilising rural towns. As one official put it:

> *The aim is not only to achieve a health outcome; it is also to achieve a social outcome. Government as a whole aims to build a sustainable community*. Official 5

Those officials, including the ones who were located in major cities, recognised that Australian society as a whole has an interest in maintaining the viability of rural life and in people continuing to live and work in rural and remote areas of the country. One senior official, however, expressed some doubts that that interest imposed any obligations on government:

> *No-one conscripts people to make them go and live there. People choose where they live. And yes, there are some sort of national interest considerations in having people living in remote areas*. Official 1

For the individual child and her family, the need to travel long distances to obtain healthcare for her has a significantly deleterious effect on the quality of life of parents, the child, her siblings and the family as a whole (401). Some officials felt that there is a case to be made for providing services close to the child's home, obviating the need for frequent long-distance travel, in order to maintain the family's quality of life, which is part of human flourishing (402) and to which health itself contributes (see sections 1.5 and 1.8):

> … *I mean health is not the only dimension to living the life people want*. Official 1

The need of rural and remote families to repeatedly travel long distances to obtain healthcare for their children is often reported (as noted in the last chapter) as having a severely adverse effect on their experience of healthcare (401). Optimising patients' experience of healthcare is agreed to be one of the goals (part of the Triple Aim) of healthcare provision in Australia and other developed countries (403). Another aspect of healthcare delivery which limits the effectiveness of healthcare

and impairs patient experience of healthcare was lack of coordination between government departments and their sub-units which deliver services.

The aim of allocating resources to coordinate health services

It is often said, in Australia in particular, that government departments and even sections of government departments operate in silos. That is, each department (such as health, education, transport or social services) tends to operate as if its immediate core business had no effect on the core business of other departments and vice versa. Even when the interaction of activity of departments is recognised, there appears to be little effective coordination between them (404). An interviewee pointe out this lack of coordination of government activities:

> … *lack of ongoing support for some paediatric services, such as specialty paediatric speech pathology and rehabilitation services which are needed to supplement the purely medical and nursing-based services which are available via the GPs and health clinics*. Official 4

Healthcare resources that are allocated by government departments or their instrumentalities consist not only of sums of money or of personnel or physical structures. They can consist of linkages and arrangements to coordinate the activities of services or parts of services to smooth the path and satisfy the needs of people who require them. The coordination of services which is needed to deliver effective healthcare is in some cases a function of officials at health department head office level, but in other cases it requires coordination at local level. Ensuring coordination of functions, though, requires policy change and motivation (on the part of officials) to make that change and to monitor adherence to that policy. One healthcare adviser pointed out the effects of service allocation without coordination:

> … *as an example: People getting airlifted to Rockhampton hospital. They get to Rocky, they have, they've been you know, medical evacuation, they turn up, you know, they're in whatever they were in when they hit the deck, they get to hospital and then they get discharged at eleven o'clock at night and they haven't got a brass razoo they're in their nightie or you know, their dirty work clothes or whatever … there's no way of getting home you know, because there's no transport and all of those logistical things and I mean the same thing happens here in New South Wales but I mean those, you know those sort of logistical things are really simple things that could be done*. Adviser 1

This lack of coordination of services was felt by interviewees to be due to incoherence of motivation: that is, absence of a commonly-held vision of what government departments and other service

providers should be providing to members of the public whom they serve. One official explained it this way:

> *The different departments and individuals within departments have competing and often complementary priorities*. Official 6

For example, according to the officials, the Federal Government sees its role as an allocator of blocks of funds to services or to groups in the community, but not as the organiser or coordinator of the exact way in which those funds are used for the benefit of individual members of the community. As well as the coordination of services, some officials suggested that healthcare programs should only be adopted if they satisfied certain delivery and monitoring criteria.

Process considerations as an aim of healthcare resource allocation decisions

Officials, especially at state level, felt that it was important to decide on healthcare programs that were based on evidence (of need, of efficacy in performing the task required of them, and of efficiency) and which had a measurable outcome by which the results of the programs could be assessed.

> … *is it proven, is this validated, is it going to achieve the desired outcome*? Official 2

As pointed out in an earlier part of section 6.2, however, monitoring the healthcare outcomes of a service in a sparse population of children with heterogeneous and sporadic needs is difficult, and the results of measurement-based monitoring may be an unreliable guide to the efficacy of the service. If continuation of a service depends on criteria such as achievement of some measurable health outcome, then a sparse and heterogeneous child population may be denied that service. Several officials observed that a part of the aim of decision-making about RA was "to do what is feasible," given the circumstances. When an intention of allocation is to locate services close to home for rural children, there are several feasibility constraints on their ability to do so. Some of these are described under the heading "Constraints" in section 6.3. Other limits on the feasibility of locating services in rural and remote areas include the limits of the workforce available locally in terms of numbers and relevant expertise. Another noted limit was reliance on private healthcare providers, including GPs, and the effect of this reliance on the nature and affordability of services.

After discussing these disparate and sometimes conflicting aims of decision-making about healthcare RA, the interviewees described the ways in which, in their experience, decisions were made.

6.3 The decision-making process

The way in which methods of decision-making that prevail in practice are perceived varies according to the role of the witness to the decision-making process – their role in making decisions about allocating healthcare resources, or in giving advice on those decisions, either as an individual or as part of a group. Participants who were part of larger-scale allocation decisions discussed the role of evidence and of economic assessment in decision-making, as well as the role of ethical considerations (discussed in section 6.5 below). Participants who were largely outside the process of decision-making about large-scale allocations also discussed the role of evidence, though their view of it was a little more sceptical; they mentioned historical allocations and political influence.

Historical allocation

When a service (such as a hospital) or a program (such as a school dental service) has been provided for some years, the population tends to assume that the service will continue, regardless of its value in improving the health of the community relative to the value of some other service on which the money might otherwise be spent. When the service ceases, there is often community resentment out of proportion to its value. This resentment could be expressed as electoral pain for the incumbent government, representing a disincentive to discontinue a historically provided service. Several officials identified this difficulty:

> *I guess the main parameter in a lot of ways is tradition and what have we always done, so it's quite challenging sometimes to make those changes or make those decisions … and reinvesting somewhere else*. Official 8

Healthcare programs for children, as one official pointed out, tend to be funded based on historical allocations and historical use. Basing allocation on history tends to militate against new allocation for newly arising needs and against the adoption and funding of new modes of patient care (see section 2.4). This is particularly a problem for rural children, because specialist paediatric hospitals (located close to urban child populations) are able to initiate programs flexibly according to need, from within their own budgets, whereas smaller rural hospitals are dependent upon health department decisions on funding allocations (see section 3.7) for re-allocation of funds to new programs, including children's programs. For new programs and in cases where resources become available by successful de-investment in older programs, most of the officials interviewed thought that healthcare programs should be adopted based on documented evidence.

The role of evidence in decisions about the allocation of healthcare resources

Participants discussed what ought, in theory, to happen: the rational allocation of resources based on evidence about need, evidence of the efficacy of a program and evidence of its cost-effectiveness. One official expressed the ideal of evidence-based decision-making:

> … *you look at the data, you identify what the need is and you look at how you might be able to address that need*. Official 3

Others outside the large-scale allocation decision-making process, however, had a different view of what happens in practice. One of the advisers interviewed noted that:

> *The bits of government that we work with, while they will say that we should be using evidence- based practice they are very poor at actually accepting that in practice.* Adviser 2

In the view of the advisers and of some officials, this limited use of evidence in decision-making about healthcare program funding was explained by other influences which constrained allocation decisions, notably political considerations (see section 6.4 below). As one adviser explained:

> *When you go looking for background on documents, background to a program or whatever, it just comes back to a funding announcement, it doesn't come back to the, you know, the why or you know, the need there was supposed to be, or it could be a very prescriptive sort of thing that's being rolled out but it doesn't relate back to the evidence about what that thing should be to address a particular problem*. Adviser 1

These comments are in general agreement with those described above (section 3.11) of surveys of Australian health department administrators and advisers which reported low prevalence of understanding and use of economic and other evidence in making decisions about the allocation of healthcare resources (235, 236). In the present study, a variety of viewpoints were expressed about what constituted evidence appropriate for RA decision-making. One such centred on statistical data, as one interviewee said:

> *If the aim of the program is to increase access to a particular health service, I mean you could measure by how many people have actually, has there been a change in the number of people who have access to a particular service*? Official 3

Another official described the presentation to decision-makers of evidence in summary form, with only the presenter having access to the original data:

> *And they* [documents submitted to shadow cabinet for decision-making about how healthcare resources would be allocated when the party entered government] *were sort of*

simplified; when I say simplified there was a lot of background material, all of it was indicated with source documents and everything. But it was sort of reduced to sort of 5–6 point plans as you do in election context. Official 2

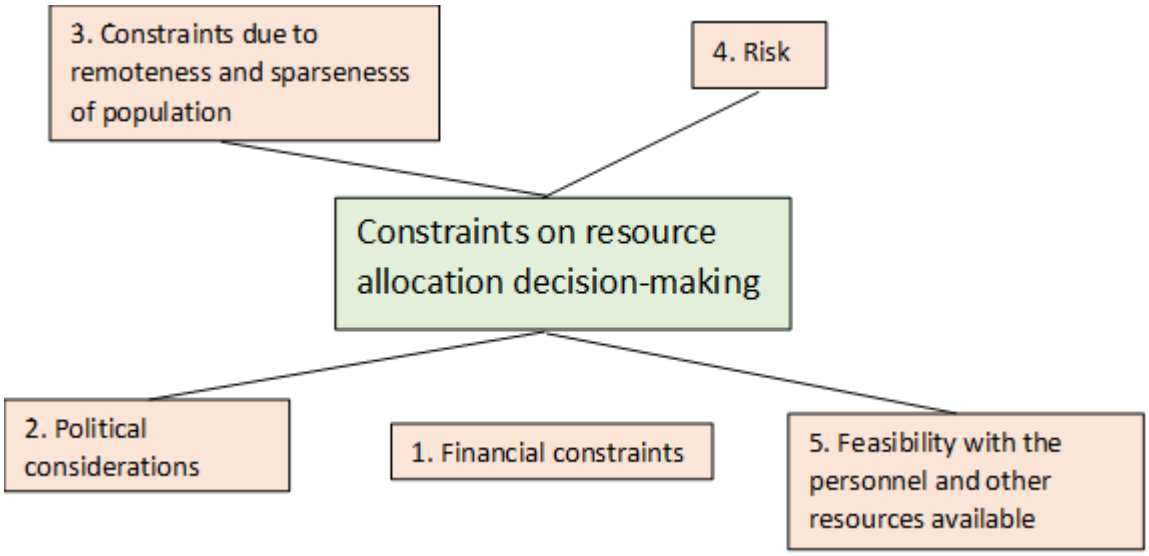
Assessment of the role of evidence in decisions to allocate services is complicated by the fact that judgement of what constitutes "adequate evidence" is essentially subjective and dependent on the circumstances (405). This problem is especially acute when rural populations are sparse and their healthcare needs are heterogeneous, and needs of a given type appear only sporadically, so that statistical evidence of those needs appears inadequate. In these circumstances, expert opinions and the advice of colleagues – which might otherwise occupy a low place in the hierarchy of evidence – may be all the evidence that exists on which to base an RA decision. Even when the introduction of a healthcare program is supported by convincing evidence of need and of the probable efficacy of the program, decision-makers are constrained in their freedom to decide.

During interviews, officials discussed aspects of the decision-making process which related to multiple themes. The next section discusses the theme of constraints on decision-making. In particular, it discusses findings about political influences on the decision-making process and findings on limitations on decision choice imposed by the need to do what is feasible.

6.4 Constraints on decision-making about the allocation of healthcare resources

There are limits to the freedom of health department personnel in deciding which services should be funded and how they should be distributed, both geographically and among segments of the population. These limits include financial constraints, the need to prioritise hospitals, limitations on the use of evidence, problems due to distance, the sparseness of population and the availability of suitable staff in rural areas, risks associated with low-volume services and political considerations. Figure 12 illustrates those constraints.

FIGURE 12 CONSTRAINTS ON DECISION-MAKING ABOUT ALLOCATION OF HEALTHCARE RESOURCES



Financial constraints on healthcare resource decision-making

As described in section 2.5, the total budget available to federal and state departments of health is set by cabinet decision in each jurisdiction and enacted by Appropriations Bills in the respective legislature. Within that total budget, at each level, there is a small amount of discretion for the minister to reallocate funds between programs and according to criteria such as need, equity or compassion. One official described this limited discretion of a minister to make an individual decision about allocation of funds to a healthcare program:

> *Depending on the amount of money that we're talking about, the minister, the minister for Health, may or may not have the ability to make a decision about moving money from one program stream to another. That will depend on the budget rules in place at the particular time, and those budget rules are set by cabinet*. Official 7

As pointed out in section 2.5, the bulk of RA is decided by cabinet, with advice from the minister and through her/him from health department bureaucrats, and input from the Department of Premier (or Prime Minister) and Cabinet, and with oversight from the relevant Treasury. These firm financial limits on the total financial resources available to a health department, imposed by the treasury of each jurisdiction, were noted by several of the officials interviewed:

> … *it's the treasurer who through submission from all the ministers and in discussion with the key participants like the premier and so on determine where the priorities will lie. And that then informs how much total, the quantum of what you have*. Official 2

With a fixed budget and multiple competing demands for healthcare, an expensive program with relatively few beneficiaries is at a disadvantage, even when there is evidence of need to support

such a program, when the cabinet and treasury oversee the order of priorities of RA. The requirement to adopt economic goals and to employ economic evidence in distributing that departmental budget is described in section 6.2. Participants described the importance to the continuation of healthcare programs, of adopting programs which have measurable outcomes and of monitoring the economic variables and reporting these to treasury and to cabinet:

> *Anyway that* [close monitoring and reporting of key performance indicators] *then became an imperative when it came to arguing with treasury where we were spending.* Official 2

That requirement of a spending department (such as health) to report target figures to the treasury, which controls overall departmental funding, may militate against allocating funds to programs which benefit relatively few people (such as rural children with a particular healthcare need), especially when the exact nature of that need may vary from one child to another. This may occur for example, in children with cerebral palsy, some of whom require physiotherapy or dietician services, while others require more frequent paediatrician or family respite care services. The urgent requirement to remain in budget can mean that anomalous means of allocating funds are adopted. For example, Activity Based Funding (ABF) means that a state receives federal funding for a service such as a hospital, based on the number and complexity of patient treatments performed by that hospital. One official noted that utilisation-based funding (such as ABF) was a much more reliable way of balancing a health department's budget than funding based on estimations of need:

> *But I said to them* [premier and treasurer], "*don't let them* [the Commonwealth Government] *deviate from ABF because if you do, we'll all go out backwards and we'll never be able to cover growth." And I still believe that to this day. I think ABF was the best thing that we ever did and if we go somewhere else it will be problematic*. Official 2

This provider-driven provision of services is not directly related to the healthcare needs of the population. ABF does mean, however, that the costs of what that hospital actually does will be covered by the funds provided, whereas if funding is determined by predicted need rather than by actual activity and if the actual cost of services provided exceeds predicted costs, then the Health department will be in deficit. The overall budget available to be spent on health constrains the choice of healthcare programs which a government can support, but within that limit, political considerations further limit the choice of programs available to a government of any political persuasion.

Political constraints in healthcare resource allocation

A political party comes into government bearing a set of political beliefs about the role of government and about the actions which a government should take, given the current and future state of the economy of its jurisdiction and the current issues (including health issues) prevalent in its jurisdiction. Given those political beliefs and the party's assessment of healthcare needs of the jurisdiction, it makes pre-election promises and is elected on the basis of those promises. Research participants were strongly in agreement that the first duty of a government is to act in accordance with the pre-election promises which it made to the electorate.

The underlying political beliefs of the party in government are major determinants of the RA decisions which that party is able to make, and consequently of the advice which bureaucrats will offer to ministers of that party. As well as those underlying political beliefs, political parties are motivated by the wish to remain in government. This means that they are also motivated, at least to some extent, by the wish to make healthcare RAs which are likely to be popular with some significant part of the electorate; this may mean the electorate as a whole, or one or more swinging seats. This use of targeted healthcare RA as a political weapon was noted by health department officials interviewed by Kirigia (265). As one of the participants in the current study noted:

> *The bureaucracy is not the only source of advice to a government. There are also political advisers whose advice may be influenced by considerations of the effect of decisions on the longevity of the government*. Official 5

In a broader sense, a government may adopt headline policies (including health policies) which may or may not make major contributions to the health or wellbeing of the electorate. These policies and their associated RAs may be decided by the minister or by the premier (in the case of state government) or the prime minister (in the case of the federal government) and ratified by the relevant cabinet. These policies are then presented to the electorate as promises. Several participants noted that hospitals and their functions were particularly sensitive for a sitting government. In particular, increasing waiting lists for services and scandals about the quality of service in hospitals can cause electoral pain for governments. This means that acute care hospitals attract funding that is out of proportion to the contribution of acute care to the health of the community, and this priority for hospitals limits the funds available for allocation to other services. It also leads to risk aversion on the part of government, which in turn leads to the location of services perceived as higher risk to urban areas, where the throughput of services is greater and hence the health outcome results are likely to be better (see below). However, even when the political beliefs of a government and the promises which it has made to the electorate do not reduce its ability to

allocate healthcare resources to people in rural and remote areas, there are other constraints on its ability to do so.

Constraints on allocation of healthcare resources imposed by remoteness

In general, the more remote an area of Australia, the more sparsely distributed is its population (406). The main constraints imposed by remoteness on healthcare RA are cost, perceived risk and the availability of suitable staff in rural areas.

Cost of treating patients in remote locations

Most healthcare services are more expensive to deliver to a child living a long distance from major centres than to a similar child living in the city. This is sometimes, though not always, the factor which determines whether the service is offered or not. Advisers to government who were interviewed felt that the greater cost of delivering services closer to home in regional and remote areas reduced governments' will to locate them there, although several officials denied that the extra cost of rural location of services affected that decision. Because there are several interacting factors (political, economic, risk, staffing and perceived need) which affect the rural location of services, however, officials were cautious about assigning particular importance to the issue of costs. As one said:

> *That depends on the political and economic calculus at the time*. Official 1

That caution also illustrates the general unwillingness of the officials to accept that any particular factor (including ethical considerations, as section 6.5 below shows) influences healthcare RA decisions.

Risk of poorer outcomes in a service which treats low numbers of patients

Locating a complex service closer to the child's home, in order to reduce travelling time and so make the service more accessible to that child carries some risks. When a service is located in an area of relatively small population (such as a town of 10–15,000 inhabitants), the number of patients who require any given healthcare activity (such as one particular surgical operation) will be low. It is known that a clinical service with a lower throughput of patients for any given treatment or procedure will have a lower success rate for that treatment or procedure than a service with a higher throughput (323, 407, 408), although other authors have cautioned against using throughput and outcome data for judging quality of healthcare (409). Because of the perceived association between lower throughput and poorer clinical outcome, location of complex or problematic services such as maternity services in regions with sparse populations is seen by health department

administrators as offering unacceptably high risks. One official expressed the governments' view of risk (both political and financial) this way:

> *Quality and safety of care is an issue. Are you introducing risk by increasing funding of small rural hospitals and services at the expense of tertiary services?* Official 6

The political risk to government lies in the electoral cost of blame which would be attributed to a department and to its minister and by extension, to the government as a whole, should a pattern of unacceptably bad health outcomes be experienced by a low-volume rural specialist health service. The financial aspect of risk lies in the increased insurance costs consequent on determination of the department's liability for poor outcomes and the resulting insurance payouts. From the government's point of view, it is perfectly reasonable to avoid risk and to deliver the highest possible quality of service. The effect of this risk aversion, however, is that services more complex or specialised than primary care or resuscitation services in EDs (described in section 1.12) tend to be located in major cities or large regional centres. One effect of this is to increase the distance that residents (including children) of more remote areas must travel to access the service, sometimes requiring sparsely distributed and infrequent public transport resources. In an appreciable number of instances, this can mean that those people (and their children) simply do not access the service. This situation was described by an adviser to health departments:

> *There's those sorts of things about making choices about whether they will access or use a service or not. And particularly if they're going to be away from home for a period of time*. Adviser 1

Staffing constraints on feasibility of resource allocations to rural areas

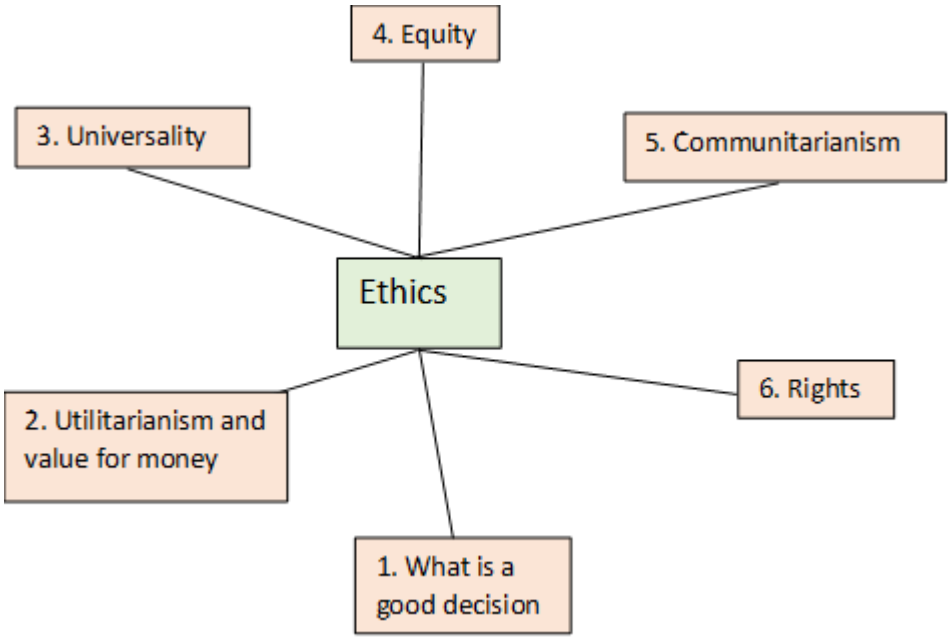
Some services which are required by only a small proportion of the population (such as child-specific rehabilitation, physiotherapy, palliative care or speech pathology services) are difficult to locate in rural areas because there are few adequately trained practitioners, and it is difficult to persuade these to relocate to a rural area where their clientele are few and where employment for their spouses/partners and suitable education for their children may be hard to find. This difficulty in attracting staff to rural areas applies to allied health practitioners as well as to medical practitioners, and according to senior officials, stipulating a rural location as a condition of obtaining a licence to practise has been found not to be feasible.

Despite all of these factors which limit decision-makers' choices about where and how to allocate healthcare resources to the population to which they are responsible, some interviewees felt that

there was some role for ethical considerations in influencing decision-making. As the next section shows, however, that role is rather nebulous and its detail and implications not well thought out.

6.5 Ethical considerations in the allocation of healthcare resources

FIGURE 14 THE ROLE OF ETHICS IN DECISION-MAKING ABOUT THE ALLOCATION OF HEALTHCARE RESOURCES



What does "good" mean in the context of healthcare resource allocation?

When participants were asked to discuss the features which characterised a GOOD allocation of healthcare resources, only one of the 11 officials and advisers interviewed mentioned moral goodness. The others described features of the process of allocation or of the mechanics of assessment of outcome which they regarded as desirable. Other participants felt that a good allocation of resources was one which satisfied a demonstrated need for a healthcare service. The issues which surround need satisfaction in RA are described in section 2.4. The question of ethical principles and their role in decision-making about RA was discussed by only one or two participants. Interestingly, senior health department officials were reluctant to agree that deciding how and where to allocate healthcare resources involved making any ethical assumptions at all or involved following any ethical principle. Several officials, in declining to be interviewed, stated that ethical principles were not relevant to their work and that they did not wish to discuss ethics. As one of them said:

> *The department does not allocate funds on the basis of ethical considerations. Budget considerations are multi-faceted and high level and seek to allocate to health agencies the*

> *funds required to meet the needs of its patients and population. Ethical considerations are typically not explicit*. Official 9

Participants in interviews did not feel that an Australian government (state or federal), the legitimacy of which depends on the social contract (see section 2.6) had any *a priori* obligations to do anything other than those things which it had promised to do before it was elected. This means that, in the opinion of the officials interviewed, unless a government had given a specific pre-election commitment to provide a stated level of healthcare or a stated level of access to healthcare, it was under no obligation to do so. Participants felt that governments were answerable (or "responsible") to the community and to those who had elected the political arm of government, but did not feel that this committed a government to performing any particular action or to act in any particular way, other than to do what it said it was going to do. This predominance of electoral promises and published policy over other considerations was expressed by one of the officials interviewed:

> … *very strong obligation to the population at large in terms of what you'd promised them*. Official 2

Pre-election promises by political parties tend to be promises of funding or of resources such as hospitals or hospital departments rather than promises of outcomes including healthcare outcomes (410, 411). When outcomes are promised, such as (the then Prime Minister) Mr Hawke's 1987 promise that no Australian child will live in poverty by 1990, they can easily prove to be unattainable (412), which militates against promises of outcomes' being made. Thus, what government officials feel that they have an obligation to provide to their population are means (i.e. healthcare resources or the funding for them) to an end (improved health of the population or of groups within the population) without promising that that end will be achieved. Beyond the context of pre-election promises, though, several of the officials interviewed felt (as pointed out in section 6.4) that their department is obliged to use the funds available to it in such a way as to achieve the best overall health outcome (for all persons in its jurisdiction). This aim to produce an overall outcome is a *utilitarian* one.

Utilitarian considerations: best overall outcome and best value for money

Several of the interviewees mentioned the need to allocate resources in a way which achieves the best overall health outcome for the limited money available. One official emphasised the utilitarian view of policymakers:

> *Resource allocations operate on a marginal basis. What guides the allocation is generally the likely outcome and efficiency of the program rather than for example, considerations of rights or Kantian considerations*. Official 6

Another official stated the position of a federal health department bureaucrat clearly:

> *I don't see myself as responsible to individuals in the community*. Official 1

This confirms the view, expressed in section 6.2, of the broad-brush aims of the Australian Department of Health. That dominant concern with overall outcomes and with efficiency, assuming that it is truly held as expressed by these officials, is not compatible with a practical concern for the health outcomes, the healthcare access or the healthcare experiences of individuals or small groups in the population, except insofar as they contribute to overall population outcomes. Within that general utilitarian framework, however, several of the officials felt that other considerations, including ethical considerations, could operate. They noted, for example, that while the need to obtain the best overall value for money spent was always present, it left room for the personal ethical principles, held by decision-makers, to operate. The role of personal ethical principles of individuals participating in group decision-making will be discussed in the next chapter. One of those principles, mentioned by two participants as if it were fundamental to the relationship between a government and its population, was that of universality.

The concept of universality in the allocation of healthcare resources

In the background of discussions about adopting policies and programs which offered the best value for the money spent, and providing extra care for the disadvantaged, was the assumption that any care which is offered should be offered to all Australians. This general assumption of universality, as expressed by the officials interviewed, appears not to take into account the various aspects of access to healthcare (section 1.10) or the practical aspects of providing such care such as distance, staffing and cost. One official portrayed it as limiting a government's ability to select recipients for a healthcare modality according to some aspect of their situation other than need:

> *There's an ethical problem with allocating health resources differently according to deserts. Universality is an important principle, especially in our society*. Official 6

That assumption of the importance of an undefined concept of universality may underlie the emphasis on equity in government documents, both state and federal, in Australia (295, 399).

Equity in the allocation of healthcare resources

Several of the officials, both at federal and at state level, and advisers felt that equity as a concept should be an important motivator in healthcare RA. In general, participants, when they discussed equity or fairness, spoke of equity of RA or equity of access rather than equity of health outcome, because healthcare RA and its effects on access are the factors most immediately under the control of health department officials. Rather than strict adherence to horizontal equity (treating equals equally), some federal and NSW officials who were interviewed appeared to place more importance on vertical equity (treating unequals unequally), at least as far as their *intentions* for RA were concerned. In the view expressed by one official, this meant unequal access to services for unequal need (see section 7.6):

> *We were looking for an overall equity, in terms of ensuring that all Australians had appropriate access to services, to mental health services. We knew that there were contributors that were preventing that from happening and so we were trying to weigh up the scales towards those who have a higher clinical need, basically*. Official 7

Among those who felt that vertical equity should be a guiding principle, there was some disagreement about whether the disadvantage that should be compensated for was greater need for healthcare, poorer access to healthcare, greater "vulnerability" or just unspecified "disadvantage". Certainly, the government documents which advocate equity as a guiding principle are not helpful in specifying which of these goals should be pursued (295, 399).

Although it seemed to be accepted by the officials interviewed that in Australian society, those who distribute benefits (in this case, healthcare resources) should do so in a way which gives some benefit to all, the idea that this should be done *because of the duties which we as members of a society owe to each other* (the communitarian principle) was not mentioned. The driving force behind the adoption of ethical principles seemed to be *noblesse oblige* rather than any recognition of interests held in common by the governors and the governed.

Communitarianism and healthcare resource allocation

There was little emphasis (or indeed mention) by the officials interviewed of the concept that RA decision-makers might base their decisions or their advice to cabinet about allocation decisions on the fact that part of who they are as moral agents (and part of who cabinet members are) is due to their being part of a community (see section 7.4). The relationship between government and community which attracted most agreement was that of the responsibility of government to its community. This was based on the fact that the political arm of government was elected by the

people to promulgate and execute policies on their behalf, and the role of the bureaucracy was to enact those policies. As one official expressed it:

> *I'm responsible to the people in my electorate … They're the ones who elected me and so they are first and foremost my top priority.* Official 3

However there appeared to be an implicit assumption by at least some of the participants that there are attitudes and expectations, held in common in Australia, and shared between government and the populace, that some things will be done by governments, including favourable treatment for some groups in the society:

> … *there is a compact* [i.e. implicit agreement] *in Australia about favourable treatment for the rural population*. Official 6

The somewhat romantic view of rural life and of the character of rural people, celebrated in literature and popular culture of 19th and early 20th century Australia, may have led to such a compact (413), but though perceived by those officials and others who have the power to make decisions about healthcare RA, it may not in fact exist in the increasingly pluralist (and urbanised) society of 21st-century Australia. Recent surveys, though, have shown persistence of popular support for government assistance for some aspects of rural life and industry, though it was less strong among younger respondents and among those born outside Australia (414).

Children and rural people are sub-sections of society which have interests and needs (including healthcare needs) which differ from those of other sections of society. Section 7.6 discusses the issues which surround giving priority in allocation of a benefit to a particular group in society (e.g. children or rural people). Equity, universality and utilitarian aims are supply-side principles which have their effect on the healthcare RA decision-maker. The rights of individuals in the population, described in section 7.11, are a demand-side consideration. If an individual such as a rural child truly possesses a right to access to healthcare equal to that of an urban child, then that secondarily imposes on others (e.g. a government department) a duty to satisfy that right. It is surprising, then, that the concept of rights which is felt to be strongly held in Anglophone societies such as that of Australia was not felt by the interviewees to be a helpful guide to RA.

The rights of groups in the population and healthcare resource allocation

The officials and advisers interviewed, acknowledged that documents such as the Universal Declaration of Human Rights (260) and the UN Convention on the Rights of the Child (415) assigned rights to citizens and to children, in particular the right to healthcare. The existence of lobby groups for these sections of the population appeared, though, in the view of the officials, not to increase,

but rather to reduce, their claim to receive extra consideration in RA. The interviewees did not appear to consider that the putative rights of population groups such as rural persons or children should receive greater weight because of particular aspects of their situation, such as remoteness of domicile or relative helplessness, than was given to the rights of other members of the population. In a Western society, where the rights that are specified in these charters are satisfied at least to some extent, the failure of the charters to quantify rights or to guide actions which may satisfy the rights of one group more than another shows the limited usefulness of such charters of rights in such societies.

6.6 Rural persons and healthcare resource allocation

Interviewees agreed that many services are more expensive to deliver in rural areas than they are in the city. They shared the view that Australian society as a whole needs people to live in rural areas and to work in the primary and secondary industries and the service industries which are located in rural areas and which supply the needs of the greater Australian society with respect to goods and national income. This supports the findings of Cockfield and Botterill's (2012) population survey (414) that both urban and rural Australians believed that agriculture is extremely important to the future of the nation and should receive more government assistance than it does. In theory, then, this reliance should impose on Australian society as a whole a duty of care and the obligation to supply services (including healthcare services) needed by workers and their families and dependents, and to optimise access to those services. The health outcomes of people in rural Australia on the other hand, were agreed to be worse than those of people who live in the city (see section 1.8). As described in section 6.2 above, at least one senior government adviser, however, felt that this did not automatically confer a right to extra consideration in the allocation of healthcare.

Healthcare advisers expressed the view that the greater expense of locating services in rural areas reduced the will of decision-makers to locate them there, but as pointed out in section 6.4, there are other constraints on decisions to locate services in rural areas, notably workforce considerations and risk aversion. Senior officials denied that financial constraints alone limit rural location of services or are responsible for the worse health outcomes of rural people:

> *People in the bush have worse health. And you're right, you can adjust for all the things you can adjust for and they've still got worse health. On the other hand, what is the solution to that, and how are we going to drive that? ... and I don't think it can be financial, because if the answer was financial, we would have fixed it by now. So I don't think it's resource allocation in that sense*. Official 1

Section 1.6 describes the various factors, other than healthcare, which affect health outcomes, and Chapter 8 discusses the prevalence of these factors among Australia's rural population and their possible influence on the health outcomes of rural children. Another factor, discussed during the interviews, which may affect the health experiences and the access to healthcare of rural people, including rural children, is the coordination of health services. This was described in section 6.2, and is further discussed below.

Coordination of rural services

Coordination of the activities of the various agencies and providers which affect the health of rural people requires a clear vision of what the health system as a whole (including public and private, state, federal and local services and departments such as Education, Housing, Transport and Social Services) is aiming to achieve in the area of rural health. In the view of the advisers and some officials, current efforts at coordination consist largely of token gestures rather than measures which are coordinated to produce a desired outcome:

> *We see repeated presentations of the same acute illness (which reflect poor social care), for example, repeated presentations of respiratory infections over a short period which may reflect social disadvantage. Rheumatic heart disease and other sorts of chronic disability often result from neglect of that sort of recurrent acute presentation*. Official 4

This problem of incoordination of services can be especially severe in the case of the health of rural children; background issues such as housing, parental education and support and the close involvement of Early Childhood Assessment and Intervention services can have an important effect on the child's health outcome (416). The views of officials and advisers on the way in which this incoordination of services affects rural children are discussed in the next section.

6.7 Rural children and the allocation of healthcare resources

The sub-themes which emerged in discussion of the position of rural children are shown in Figure 15.

Inadequacy of healthcare services for rural children

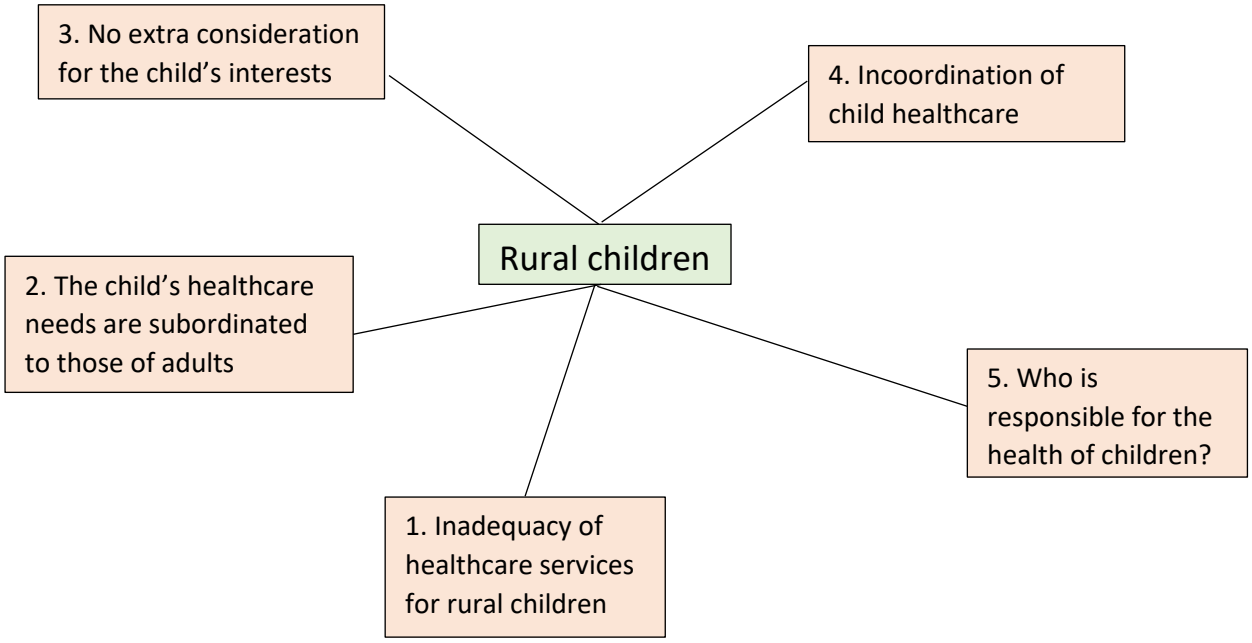
As pointed out in section 1.13, children are dependent on adults for their access to healthcare, and the interests of the unwell child may conflict with those of the parents, siblings or the family as a whole. Because children typically make up only 20% or less of the total population of a region of NSW, rural specialist services such as orthopaedics, physiotherapy, speech pathology, rehabilitation and palliative care are aimed at the care of adult patients, and there are rarely personnel with expertise in the care of children in such services located in rural areas. Those that are located

outside major cities tend to be in regional cities such as Orange, Dubbo, Wagga Wagga or Armidale. The effect on the child and on her or his family of this central location of specialist services with expertise in catering for the healthcare needs of children is described in the next chapter.

The rural child's healthcare needs are subordinated to those of adults

Decision-makers in capital city health departments tend to take a broad-brush approach to the treatment of illness categories. This approach is likely to perpetuate the current situation of provision of adult-specific services in rural areas, which leave the child population of an area under-served.

FIGURE 15 SUB-THEMES OF THE THEME OF ALLOCATION OF HEALTHCARE RESOURCES TO RURAL CHILDREN



This whole-of-population approach to the provision of healthcare services was articulated by one interviewee:

> *I mean, we don't identify age groups, we look broadly at the population that you have and you would, based again, we want to meet everyone's health needs. We don't go "we'll do the kids because, for whatever reason, or we'll do the adults," we broadly look at what are the health needs of our community broadly*. Official 3

This adult-centric view of service provision is essentially a utilitarian one, and is based on a perception of where the majority of needs lie. As adults make up 80% of the population, the majority of healthcare needs are adult needs. Similarly, the majority of needs for an individual healthcare modality such as physiotherapy, are adult needs.

There should not be extra consideration of the needs of children

In addition to this utilitarian approach to RA, the perception of the officials appeared to be that healthcare needs of children as a group were somehow less than the needs of adults, suggesting limited focus on the interests of the child. For these officials, this justified a lesser provision of services to children as a group than that provided to adults. As one expressed it:

> *I'm sure there are individual children who would benefit greatly from having Commonwealth money spent. But as a group, children's needs are considerably less than low-income adults*. Official 1

Although the officials acknowledged that location of services far from home was a disincentive for individuals and families to access those services, they also felt that overall, children would be better off attending high-volume specialist paediatric services in major cities than lower-volume services located in rural areas, however those were organised:

> … *the more you spread out highly specialist services, like children's oncology, the less quality service you'll get in those places*. Official 1

This perception that considerations of risk (see section 5.4) outweigh those of service access and utilisation was shared by health department officials, whereas the external advisers placed more importance on the ability of families to access the service.

Incoordination of healthcare for rural children

Coordination of care of the rural child, especially in early childhood development, is a major deficiency in the current whole-of-government arrangements, both at federal and at state level, although there is some recognition among decision-makers and advisers that this is a problem that must be solved. One adviser expressed the urgency of the problem in this way:

> *I think we should start putting our money where our mouth is around early development and stop talking about how important it is and actually invest in that*. Adviser 2

The efforts of any one government department or healthcare provider to rectify problems which are perceived only by that department or provider are rendered nugatory by lack of coordination between the activities of local government and individual departments such as Health, Education, Transport and Social Service, between federal and state departments, and between government departments and private healthcare providers such as GPs. Although individual departments monitor their own activities and outcomes, usually in statistical terms, the contribution of the

activities or lack of activities of other departments and agencies to those outcomes, according to the officials and advisers, is not acknowledged or acted upon.

Who is responsible for the health of children?

The officials interviewed appeared to be of the opinion that although the child's relative dependence on adults should be taken into account, offering extra support to children and extra consideration of their interests because of that dependence was not the business of government. Several interviewees expressed the view that parents had the responsibility to ensure that their children had appropriate access to healthcare and that they could be relied upon to ensure that this was the case, even when the interests of the child conflicted with those of the parents.

6.8 Summary

This chapter examined the aims and methods of decision-making about the allocation of healthcare resources from the point of view of officials, both elected and non-elected, at federal and state levels in Australia. Some of those officials were in a position to make decisions about the allocation of resources, but most were advisers to the decision-makers. The chapter also examined factors which restrict the options of decision-makers and which restrict the advice that can be given to them, and the way in which decision-makers perceived their obligations to rural persons, including rural children.

It became clear from the interviews that there is a hierarchy of power to make RA decisions. The premier or prime minister has the most power to make priority decisions, but most decisions about where departmental funds should be spent are made by the minister, advised by departmental officials. The power of officials lies in their choice of advice to offer the minster on RA.

Interviews revealed that aims of decision-making about RA were conflicting. The overall aim appeared to be the satisfaction of identified healthcare needs, though ability to do this was limited by availability of relevant information and, in the case of rural children, by the fact that specific needs occur sporadically in a geographically sparse population.

Economic efficiency was seen as a background aim which allowed decision-makers some scope to act according to their own values. The fulfilment of electoral promises and maintaining electoral popularity were seen as major determinants of decisions. They were also seen as aims, which often conflicted with the use of evidence about needs and with evidence on the economic efficiency of allocations or of programs. The coordination of care among government agencies and with other providers was noted to have a major impact on healthcare outcomes and on patient and family

experiences of healthcare, but its implementation was portrayed as patchy and inadequate at present.

Many decisions to allocate funds to ongoing programs are made because of historical allocations, because discontinuing current programs is politically difficult. Evidence of the need for or the efficacy or efficiency of a program received lip service, but its role appears to be limited by the dominance of other factors just mentioned. The constraints (which operate both on ministers and on bureaucrats) on RA decision-making include political ones (in particular, the political beliefs of the party currently in power and the effect of decisions on electability) and economic ones. The latter include the overall budget and the perceived need to achieve the best overall health outcome for the population with the funds available.

Ethical considerations have only a minor influence on decision-making, and some officials denied that they have any influence at all. When officials discussed the question of what made a RA decision a good one, only one official mentioned moral goodness. Satisfying healthcare needs though, was seen to be an important aim of government, and "equity" was regarded as important. It was not clear though, even from individual officials, whether the primary focus of their efforts to achieve equity should be on equity of RA or on equity of access to healthcare for individuals in the population. Because of this ambiguity, it was difficult for officials to determine whether equity was being achieved.

Officials felt that one of their goals should be the utilitarian one of achieving the best improvement in the health of the population that could be achieved with the funds available. They felt that this should be done as efficiently as possible, and federal officials, in particular, felt that their concern and duty should be towards large groups in the population rather than towards individuals. The interests of subgroups in society was seen by other officials as deserving some consideration. Children and rural people though, were seen as having sufficiently active and effective lobby groups acting on their behalf that their interests could be catered for through the political process without an extra duty being imposed on government to give extra consideration to their interests.

The interviewees did not believe that the rights of individuals or of minority groups in the population (such as children or rural people) were an important consideration in the allocation of healthcare resources, despite Australia's being a signatory to the Universal Declaration of Human Rights and the United Nations (UN) Convention on the Rights of the Child. While the provision of healthcare close to home was seen as desirable and conducive to the utilisation of healthcare resources when these were needed, the actual achievement of this was constrained by considerations of cost (in particular, opportunity cost), risk and workforce availability. It was acknowledged that Australia as a whole

needs people working and living in rural areas, but it was not felt that this need per se imposed an extra duty on government to cater for the interests of rural people, although it was agreed that, traditionally, there was a compact between government and people in Australia that extra consideration be given to the interests of rural people.

The dependence of children on others to look after their interests was not seen as imposing an extra duty on government, because parents and lobby groups were seen as effective advocates for the interests of children. The fact that the needs of sick children are heterogeneous and sporadic was acknowledged, but those needs were noted to be subsumed in the healthcare needs of the whole population, of which the majority are adult needs. Healthcare advisers asserted that this meant that the needs of sick children are often not effectively catered for close to home. Several participants noted the issue of coordination of care and the unfulfilled duty to arrange and supervise it, but officials were silent on the question of who should organise and supervise the coordination of government activities at the various levels of government function at which it is seen to be required.

The next chapter considers the ethical frameworks which *could* guide healthcare RAs that affect rural children. The following chapter reviews the suitability of those frameworks for that purpose.

Chapter 7: Possible ethical frameworks

7.1 Overview of ethical frameworks in healthcare allocation decisions

All decisions about the most appropriate way of allocating healthcare resources among a population involve making some ethical assumptions about what is a good decision. Even decisions made on what appear to be purely economic grounds involve some assumptions about what is good. These assumptions may be that one should aim to achieve the best overall value for the money spent (a utilitarian assumption), or that all persons should receive an equal share of the resources allocated (an egalitarian assumption), or one of several other possible ethical principles.

In order to discover a set of ethical assumptions that is appropriate for making RA decisions that affect rural children, the range of ethical assumptions that may be relevant to such decisions is reviewed first. John Rawls' approach was to propose an "ideal theory" which might be appropriate in an ideal world where strict pre-conditions obtain, and then use that ideal theory to construct a "non-ideal theory" to guide decisions in the rather messier real world, where those strict pre-conditions do not obtain (417). The next sections describe the "ideal" ethical principles which might guide healthcare RA, and the next chapter describes how these might be compared and their suitability assessed in the non-ideal real world of allocation of healthcare resources to the heterogeneous Australian population.

The ethical principles considered here which might guide RA decision-making by government health departments are libertarian, empirical, utilitarian, egalitarian and equity, prioritarian and rule of rescue, communitarian, compassion, rights and justice. Virtue ethics are not discussed, first because it does not provide a clear-cut guide to action in individual decisions (418, 419), and second, because while it may guide decision-making by individuals, its applicability to decision-making by groups or by organisations like health departments is questionable. Chun (2005), having studied the ethical values of 158 companies and surveyed 2548 of their customers and employees, concluded that the virtues relevant to organisations were integrity, empathy, warmth, courage, conscientiousness and zeal (420). It is difficult to see how adherence to these or similar virtues could guide the kinds of decision that groups of health department officials must make, and in particular, how adherence to any or all of these virtues would make any difference to the current rural–urban difference in health outcomes of Australian children. Published literature on the role of virtue ethics within government organisations tends to discuss the espousal of virtue by individuals within the organisation rather than by the organisation as a whole (421).

7.2 Libertarian

The basic tenet of libertarianism is that an individual has full ownership of himself. That is, he has complete liberty to use himself and his natural attributes (including such attributes as allow him to accumulate wealth) and to retain or dispose of the property (including money) gained by the use of those attributes, as he pleases (258, 422, 423). A libertarian would hold, for example, that the state is prohibited from forcibly sequestering as taxes, any part of the wealth of an individual in order to distribute it for the benefit of the disadvantaged (e.g. the sick) or to build and run hospitals or pay pensions (422) or to supply public infrastructure such as roads or a clean water supply.

Since in a libertarian system the state is forbidden to raise taxes other than for some minimal level of policing (to prevent the interests of persons from being encroached upon by others), there is no provision of healthcare by the state (422). The individual is responsible for supplying his own healthcare needs, financed from his own resources or by health insurance for which he pays the premiums from his own resources. According to libertarians, healthcare is not a right, but if an individual chooses to donate to better the healthcare available to another, that is done as a charity (424).

If healthcare is not provided by society, then individuals or their private insurance must pay for their own, and healthcare is allocated according to the ability of the individual or his insurance to pay. Because the emphasis is on the welfare and choice of individuals (both providers and consumers of healthcare) rather than on the welfare of all members of the society or of the society itself, healthcare providers (individuals and healthcare corporations) can choose the services or programs that they wish to provide, based on the ability of provision of that service or program to satisfy their own preferences. This means that not all classes of healthcare needs will necessarily be satisfied, and the needs of some classes of patient may remain unsatisfied unless some healthcare provider comes to believe that it is in its own interests to supply the means to satisfy those needs.

When healthcare allocation is guided by libertarian principles, the mode of allocation is that of the free market on the precept that a free competitive market will always lead to better overall outcomes than a regulated system of RA. As Petrou and Wolstenholme (2000) pointed out, however, there are several problems with the free market model of healthcare RA which prevent the market operating freely. First, the consumer is always less informed than the healthcare provider, which limits the ability of the consumer to make a free, adequately informed choice. Second, the market cannot deal effectively with a large number of complex and interacting medical and social problems whose status and responsiveness to treatment is often uncertain. Third, insurance companies' pricing policies tend to encourage the young and healthy to opt out, leaving the old and the

chronically ill to pay premiums high enough to support the companies' expenditures. For some people these premiums are unaffordable, leading to a pool of poorer, older, more chronically ill or otherwise disadvantaged people who have no access to healthcare (154). For example, people living in small or isolated rural communities may only gain access to healthcare if it is in the interests (financial and other) of a provider to supply the healthcare. In practice, all organised societies provide some amount of publicly funded healthcare, so that healthcare resources are not allocated exclusively according to the ability of individuals to pay (154).

7.3 Empirical

The word "empirical" in this context can refer to two different ways of making decisions about healthcare RA. The first refers to the use of empirically derived information about the frequency of illness in a population and about the prevalence in that population of factors which predispose to illness in general (425). The second refers to the process of consultation with members of a population about the grounds on which healthcare RA decisions in general should be made (335). This section discusses the first use of "empirical"; the second use of the term is discussed in section 3.14. Public consultation on healthcare RA decision-making in the Australian context is discussed in sections 3.8 and 3.13 – 3.16.

In general, the intention of empirically-based capitation formulae (see section 2.4) is to provide equity in the allocation of healthcare resources between geographic regions of a country or state. In the case of the UK's NHS, the stated aim was to ensure "equality of opportunity of access to health care for people at equal risk" (426). This aim says nothing about actual access achieved (only about opportunity for access), nor about equality in the quality of care which is available in individual regions (426), nor does it mention compensation for health disadvantage.

The observations used in such capitation formulae may be of indicators of burden of need (such as the age profile of an area, or the proportion of its population which is Indigenous) (427) or of indicators of resource utilisation (such as DRGs and their derivatives, which are indicators of hospital use or GP visits per head of population).

Necessarily, observational data reflect the state of the world before the current allocation decisions are taken. Hence, even if they gave a complete and reliable indication of need or usage at the time the observations were made, they are vulnerable to unreliability because of changes in population numbers or composition, or in patterns of resource use (such as a change in emphasis from overnight hospital stay to day care, or an increase in hospital in the home care).Funding according to utilisation disregards the fact that utilisation is to some extent supply-dependent and that

inadequate supply of a resource may lead to deceptively low utilisation rates. If those low utilisation rates are used to guide future RA, some population groups may continue to have unmet healthcare needs unless some untied financial provision is made for those unidentified unmet needs (426). Over-supply of a resource can result in high utilisation in relation to need, and reliance on utilisation rates will perpetuate the disproportionate allocation of resources.

Capitation funding systems are based on some empirically derived estimate of need. The most detailed and sophisticated of these systems in the world at present (the NHS weighted formula for allocating healthcare resources among geographical regions in each of the UK's countries (428)) attempts to minimise unmet need across all health regions by weighting the average per capita allocation to each region according to 19 sequentially-added variables (426). Less complex and less sophisticated capitation formulae, such as that by which financial resources for healthcare are allocated among healthcare regions in NSW, and that recommended for RA among the 49 counties of Ontario, Canada (175), permit much more variability in RA per capita, but to compensate make provision for unmet need. Despite that, it has been pointed out that the NSW formula (at least, before the 2012–13 modification), permitted considerable inequality in financial allocation per capita between healthcare regions (265, 429).

7.4 Utilitarian

Utilitarianism is an ethical theory which holds that actions (including decisions about healthcare RA) are right if they produce more utility (including welfare or wellbeing) for all people affected than any other action which is available to the actor (or decision-maker) at the time (430). A right action is defined as one that maximises the good (however "good" is defined) (45). The next sections discuss the issue of the nature of utility as it bears on the allocation of healthcare resources. Utilitarian theories are a subgroup of consequentialist moral theories, which hold in general that it is the consequences of actions which determine their rightness (431). Some utilitarians insist that a moral theory is only utilitarian if it is agent neutral (that is, if – according to that moral theory – the rightness of an action does not depend on who performs the action, then the theory is a utilitarian one (432)).

Actual versus foreseeable consequences of an action

Some utilitarian theories maintain that it is the actual consequences of an action which determine its rightness (objective utilitarianism), whereas others hold that it is the foreseeable consequences (and in particular those consequences that are foreseeable by the agent) which determine the rightness of an action (subjective utilitarianism) (430, 431). A theory which insisted that all consequences be

taken into account would mean that unexpected, random events would influence whether an action was right or not, and a theory which insisted that all foreseeable consequences be included (even if these were not foreseeable by the agent) would make the unreasonable demand of complete knowledge of consequences before an action could be described as a right action (430). In practice, an agent can rarely foresee all of the consequences, beneficial and harmful, of the action she proposes and of alternative actions. Furthermore, the cost in terms of time and benefits, to all concerned, of obtaining the necessary complete information may be greater than the benefits to be gained by the action, and the agent may make mistakes in comparing the benefits and harms (433).

Act utilitarianism versus rule utilitarianism

Act utilitarianism (434) judges the moral worth or rightness of an action by the net benefit (for a description of benefits, see below) of that action for all affected by it. Rule utilitarianism, on the other hand, judges the moral rightness of a behaviour-guiding rule (e.g. “never kill a person” or “always keep your promises”) by the overall net benefit for all affected if that rule is followed. In rule utilitarianism, an action is morally right if it follows that rule (430).

As G. E. Moore pointed out, the net benefit of an action is the difference between the total benefits caused by the action, summed across all individuals affected by the action, and the harms caused by the action, summed across all individuals affected. Thus, the action which causes the greatest total benefit may not deliver the greatest net benefit if it also causes great harms (435). The process of summation, however, means that the greatest net benefit (and therefore the most right action according to act utilitarianism) may be produced by an action which causes significant harm to some individuals. Further, the process of summation does not ensure equality of benefit among those affected by the action (45).

This requirement for summation of net benefit carries major disadvantages for act utilitarian theories. First, it can demand severe harms and denial of rights to some individuals. For example, if killing one innocent person is required to save the lives of three others, then that is the action that act utilitarianism demands. Second, it can require actions that we regard as truly dreadful. For example, if it was necessary to torture a small child to obtain information in order to prevent a bomb blast that would kill many people, a strict act utilitarian theory would require that the child be tortured (431, 436). These violations of the rights of individuals can be limited by the application of side constraints, for example limiting the actions available to you to those which don’t violate certain rights of individuals (such as the right to life). It can be argued however, that when side constraints are applied, such as “do not violate an individual’s right to life,” then that becomes a criterion by which the moral rightness of the action is judged (437).

The disadvantages for act utilitarianism, of summation, rights violations, inequality, decision-maker biases and incomplete knowledge of likely outcomes, are to some extent avoided by rule utilitarianism, in which moral rules or precepts are followed, which in general, over a range of sets of circumstances, deliver better overall outcomes than alternative rules. A major problem, though, is that while any given rule may give the best overall outcomes over a range of similar circumstances, it may foreseeably fail to do so in some individual set of circumstances. If the rule is modified from *In circumstances x_n, do y*, to *In circumstances x_n, do y except in circumstance x_i*, then the rule could be further modified the next time an obvious exception occurs, and so on until rule utilitarianism collapses into act utilitarianism (433). The rule utilitarian's reply to this problem is that in rule utilitarianism, the anticipated benefit is not maximised by the agent's conforming to individual rules, but rather by her accepting them (433). Further, Hooker claimed, rule utilitarianism is committed to two principles: that rules are chosen only because of their consequences, and that those rules determine which sorts of action are morally wrong. In Hooker's view, rule utilitarianism makes no commitment to maximise expected benefits (433).

What is a benefit and what is a harm?

In classical utilitarianism (434, 438, 439), what is to be maximised across all individuals affected by an action is pleasure, and what is to be minimised is pain. The pleasure to be maximised and the pain to be minimised in this hedonic view of benefits and harms may be actual sensations, or they may be states of mind, induced by pleasing or displeasing states of affairs. While it has been argued that some kinds of pleasure are intrinsically more valuable than others (e.g. it is suggested that aesthetic pleasure is more valuable than physical pleasure, and that the pleasure of schadenfreude has a still lower value), the allocation of different amounts of value to pleasures by individuals other than those experiencing the pleasure is merely arbitrary (431). Empirical studies of the hedonic view of subjective wellbeing describe three components: life satisfaction, the presence of positive mood and the absence of a negative mood (440).

G. E. Moore added the values of beauty and knowledge to the list of benefits to be maximised (435), while others have suggested that friendship or love, freedom or ability and life should count as benefits (431). Amartya Sen suggested that what should be maximised is some combination of happiness and capability, and that anything that reduces these is a harm which should be minimised by an action if that action is to be considered morally right (441). If there is more than one kind of benefit to be maximised, then individuals may experience different amounts of each type of benefit, and the amount experienced is subjective and dependent on the state of circumstances, knowledge and background of each individual. Furthermore, dimensions of benefit (such as knowledge and

love) may be incommensurable, unless they can be related to some single, overarching variable such as happiness (442), in which case, the overarching variable is the single benefit to be maximised.

Preference utilitarianism

Another type of benefit which, it has been suggested, should be maximised in a utilitarian ethical system, is the satisfaction of preferences. A preference is a desire that the world should be a certain way (e.g. I have a preference not to be in pain or I have a preference to have free access to drinking water). When preferences are used as proxies for personal utility, many preference utilitarians would exclude those preferences based on inadequate or misunderstood information or on cognitive biases (430). Similarly, some utilitarians exclude antisocial preferences and other-regarding preferences (those which assign goods to others) from consideration (430). Excluding other-regarding preferences, however, dismisses an important part of the utility of some individuals. For example, many people, given a choice between a long life for themselves and a good education for their child, would prefer the latter. This point has considerable importance for the quantitative and geographical distribution of healthcare resources.

Preference utilitarianism holds that the right action is that which satisfies the greatest number of preferences (summed across all those individuals affected) to a greater extent than any other action available to the agent at the time. To any individual, some of her preferences are more important than others, so when the aggregate of preferences is assessed, those which are more important to the individual are weighted more heavily than those which are less important to that individual. From the point of view of an agent, there are no means of comparing the overall preference satisfaction of two or more individuals, given that a given preference may hold different importance for each, and the degree to which that preference is satisfied may have a different effect on each individual's wellbeing. Furthermore, as each individual carries a unique bundle of preferences, interaction between those preferences and the degree to which each is satisfied by an action will produce a unique effect on each individual's wellbeing, which the agent has no means of comparing with that of other individuals (443).

Importantly, there are many contributors to an individual's wellbeing, other than health state, and these are reflected in the individual's bundle of preferences (440). These non-health contributors may include such things as feelings of self-worth, the existence and closeness of relationships within the family and with friends, satisfaction with the nature of one's work and one's competence at it, and the availability of leisure time and of ways to occupy it (440). The nature and importance to the individual of each of these will vary with age, gender, physical circumstances, cultural background, socio-economic status and many other factors, and will vary during the individual's lifetime. Because

these non-health factors can be major contributors to wellbeing and because they can be strongly affected by healthcare allocation decisions, individual preferences about them should be included in any calculus of overall preference satisfaction of any healthcare RA decision.

Preference utilitarianism underpins the economic arguments of cost-utility analysis; in particular, the empirical valuation (via survey) of the quality of life delivered by healthcare interventions or programs. The principle of CUA (see section 2.4) is that the right intervention or program is that which can be shown to lead to the greatest number of years of life, across all individuals affected, adjusted for quality by a weighting based on assessment, by the many individuals surveyed, of their own quality of life. This assessment, in turn, reflects the preferences of those individuals for the way their life should be and the way in which they should be able to function. A major problem for this preference-based weighting method is that individuals are only surveyed once, while their actual health state will vary over their lifetime, and the valuation by the individual of that health state varies with their stage of life. Thus a degree of disability which seemed acceptable to an 18-year-old may appear much less so to her when she becomes pregnant or has young children, but much more so when she has a sedentary job and the children have left home (444).

In some ways, preference utilitarianism pays respect to the individual's autonomy (in that individuals are surveyed for their health state preferences) (430), so that in theory there is less room for paternalism by clinicians or healthcare decision-makers than with other forms of utilitarianism. In practice however, not every individual affected has her preferences sought, while the allocation of weight to preferences and the choice of which preferences are legitimate and which are not still lies with the agent.

Utilitarianism in public policy

Robert Goodin (445) argued that because of the nature of rule by consent of those ruled, public decision-makers are obliged to be concerned with outcomes, which means that they must be guided by some form of consequentialist ethical system. He argued that rule-based deontology is unsuitable for a decision-making process that must be responsive to the wants and needs of a population (445). He suggested that the agent position of public officials, including those who make decisions about healthcare RA, is different from the agent position of private individuals in the way in which they must make ethical choices. While private individuals have detailed knowledge of their own circumstances and usually have fairly detailed knowledge of the effects that their actions are likely to have on others, public officials have summary knowledge of their own situation and statistical information of the likely effects of their actions on populations rather than the detail of their likely effects on individuals (445). For this reason, Goodin argued the public official is forced to adopt a

form of rule utilitarianism rather than act utilitarianism, which would require more detailed knowledge of the circumstances of those individuals likely to be affected by a decision (445).

Goodin claimed further that the most suitable form of utilitarian framework to guide the government decision-maker is a modification of preference utilitarianism. A public official has no means of becoming aware of all of the actual preferences of those affected by a policy decision, so must make assumptions about what those preferences are. The official assumes that an individual would prefer things that improve her welfare in ways that the official can foresee. The paternalistic nature of this "welfare utilitarianism" (445) is dictated by the macro scale on which RA decisions are made.

7.5 Equality

The term "egalitarian" describes those who believe that equality is a good which should be pursued. The next section discusses reasons for that belief.

Why should we regard equality as good in itself?

Those who regard equality as an intrinsic good generally do so on the grounds that humans are fundamentally of equal moral worth and of equal moral status, and that therefore they and their interests should be accorded equal respect (446). This belief is widely shared (see "Bentham's dictum", quoted by J.S. Mill in *Utilitarianism, liberty, and representative government*: "Every man to count for one and no one to count for more than one" (439)). Equality may be supported on Kantian grounds ("Act only according to that maxim whereby you can, at the same time, will that it should become a universal law" (206): i.e. that all agents should act similarly towards all others means treating their interests with equal respect); on contractarian grounds of mutual respect or on consequentialist grounds (e.g. a society in which all members are regarded as morally equal may be more socially cohesive, peaceful and mutually supportive than one in which the interests of some members are regarded as more important than those of others).

There is some dispute about who or what should be regarded as having equal interests; should it be all humans, all persons (this might exclude infants and young children who are potential, but not actual, moral agents, and the severely cognitively impaired who may never become moral agents), all sentient beings (this might include higher primates, or even other animals)? The term egalitarianism, as Parfitt described (447), encompasses a range of beliefs, including the following.

Teleological (telic) and deontological (deontic) egalitarianism

Telic egalitarians believe that a situation in which some persons are worse off than others is bad in itself. This situation could be rectified, in their view, either by providing advantages to the worse off, to bring them up to the level of the best off (one group gains and no-one loses), or by removing benefits from the best off to bring them down to the level of the worst off (one group loses and the other may or may not gain, depending whether the benefits are redistributed to them). There is nothing in the pure telic egalitarian belief to indicate that one is preferable to the other. This levelling-down issue has led many to reject pure telic egalitarianism (447).

Deontic egalitarians on the other hand, believe that while there is nothing wrong with a situation in which there is inequality, performing an action which results in inequality is bad because it is unjust (see section 7.12) (447). In the context of healthcare RA, an existing situation in which rural children receive less healthcare than urban children is bad in the opinion of telic egalitarians but not in the opinion of deontic egalitarians. A new decision to allocate more healthcare resources to urban children than to rural children that has the effect of increasing the disadvantage of rural children is bad from the point of view of both telic and deontic egalitarians. The importance, for the present study, of the difference in the two types of egalitarians is that telic egalitarians are motivated to act to rectify an existing disadvantage (for example by reducing the healthcare available to urban children so as to redistribute it to rural children), whereas deontic egalitarians are motivated to perform actions that don't increase relative disadvantage but rather tend to reduce it (e.g. by allocating new resources to rural children) but are not motivated to remove any resources from urban children.

Pure and hybrid egalitarianism

A hybrid telic egalitarian may combine a belief that inequality in welfare is bad, with a utilitarian belief that she should act so as to increase aggregate welfare. This motivates her to act in a way that improves the situation of the worse off, without worsening that of the best off (447). Equality is most often regarded as a mandatory guide to action, but it might be more usefully seen as an ideal which should be pursued when circumstances permit (446). This may be a more realistic way of approaching the concept of equality, especially when there are many different aspects to equality of healthcare RA (see section 7.5), and many ways in which individuals may possess prior advantage or disadvantage, and many ways in which RA affects the overall level of advantage of an individual. Furthermore, levels of advantage and disadvantage are very difficult to measure and to compare among modalities of advantage and disadvantage, especially as they are subjectively experienced

differently from one individual to another, according to the circumstances, personality and prior experiences of those individuals.

Equality in health and healthcare

Equality and equity in the distribution of healthcare resources have received much attention since the Black report (*Inequalities in Health*) commissioned by the UK Government and published in 1980 (448). Authors have used the two terms to mean a variety of things (see below) (449) and sometimes authors have used them to describe the same concept (449-451). To avoid confusion, the term "equality" is used here as a purely descriptive term, and "equity" when a normative meaning is intended (452).

To say that two things (or people, or groups of people) are equal does not mean that they are identical; indeed the use of the term "equal" implies that the two things differ in some respects (e.g. their position in time and space) but are the same in some other relevant respect, and a full description of the equality of those two things requires a statement of the characteristic which they share (450),for example, "those two boys are equal in height" or "those two families are equal in their household income." Mooney (2003) described seven possible meanings for the term "equity" (sic) as it refers to allocation of healthcare resources, all of which apply equally to the descriptive term "equality" (453). These meanings are outlined below.

Equality of per-capita expenditure

When an overall budget is allocated among health regions, the population of each region may be one determinant of the funding allocated to it, as seen in the NSW and NHS (UK) funding formulae (427, 428). This is a supply-side consideration, and although it could be claimed that each citizen should receive an equal share of the amount which the central treasury (national, state, province or region) spends on healthcare, equality in per capita expenditure takes no account of differences in burden of illness or of socio-economic, geographic or other disadvantage, nor of the differences between regions in costs of healthcare delivery, nor of the experienced needs of individuals or populations (211).

Equality of per capita resources supplied

This takes account of the fact that the provision of some healthcare resources is more expensive in some regions than in others. For example, the large travel distances in rural areas mean that transport costs for delivery of hospital and clinic supplies are much greater for the same level of service delivery in rural areas than in the city. Similarly, economies of scale mean that the same services can be delivered more cheaply in large urban hospitals than in smaller rural hospitals. This

definition, too, takes no account of need (211). This manner of distributing resources takes account of the principle that all persons should be treated as moral equals, but takes no account of the fact that persons in different circumstances require different bundles of benefits (454). Since some will be better able to take advantage of the goods supplied than others, strict equality of RA can lead to very large inequalities in outcome (454).

Equality of resources supplied for equal need

This form of equity makes allowance for the difference in cost in providing a given service in geographic regions, but contains no provision for equity in access (e.g. affordability, appropriateness to need, acceptability (e.g. to the elderly, to women, to adolescents, to the disabled or to cultural minorities) or geographic access, including the availability of transport. It says nothing about where the service will be provided in relation to the patient's homes, so that in a large Australian state, a service for a rural patient could be provided in the state capital, thousands of kilometres away. It says nothing about the quality of service provided to people in different regions (e.g. the most modern equipment, the most experienced practitioners).

The age and sex composition of a population and the prevalence of known morbidities and contributors to ill health (e.g. poverty or indigenous status) in that population may be taken into account in any funding formula. These factors are determinants of the illness burden of that population and hence of its need for healthcare, which may be taken into account in decisions about allocation of funds between population regions (see section 2.4 for a discussion of the NHS funding formula and that formerly in operation in NSW (427, 428)). The problems with this definition are the lack of agreement on what is "need" (211) (see section 2.4) and who is to judge the magnitude of needs.

Equality of opportunity for access to healthcare for equal need

As discussed in section 1.9, there are several dimensions of access to healthcare. Equality of opportunity for access means that individuals with equal healthcare needs sustain equal costs to themselves in gaining access to healthcare. Those costs may be in the form of transport costs or of income forgone, or social and emotional costs of separation from family or friends, or the physical costs of healthcare forgone when the available healthcare is too far distant or is for some reason unacceptable, or is forgone because the cost of accessing it appears to the individual to be too great (453). If this form of equity takes into account all of the components of access (section 1.10), ensuring equity of opportunity for access to services delivers supply-side equity, provided that the quality of those services is equal in all regions. This is horizontal equity (that is, equal needs are treated equally), and does not offer extra care to the disadvantaged (vertical equity). Furthermore, it

does not supply the educational, transport or other services which would be needed to ensure equality in service uptake (demand-side equity).

Equality of utilisation for equal need

Mooney pointed out that using utilisation rates (such as GP visits or hospital admissions per capita) to measure opportunity for access is flawed, as utilisation depends both on supply of the healthcare resource and on demand for it, whereas opportunity for access depends only on supply of that resource (453). Therefore, according to Mooney, whether or not the opportunity is used is not relevant to assessment of equality of access (453).

Equality of utilisation will only be the same as equality of opportunity for access for equal need if all individuals have the same preferences, the same abilities and the same information and understanding (453). If the aim of healthcare RA is to achieve equality of utilisation, it may be necessary to allocate extra resources (e.g. education, organisation, structures such as clinics and patient transport) to some groups of patients, such as indigenous communities and the disabled (279, 453).

Equality of marginal met need

If each region were to arrange its healthcare needs in order of priority, equality of marginal met need would be achieved when resources are distributed among the regions such that the final need which is met on the list from each region is the same. The problem with accepting that such a distribution is equitable (see section 7.6) is that it depends on the assumption that the order of priority ranking is the same in all regions (453). This may often be an incorrect assumption; for example, a region with a large elderly population may place a much higher priority on home visiting services than a region with a smaller elderly population.

Equality of health

All of the previous definitions of equality of healthcare are ways of looking at equality in *allocation* of financial or other types of healthcare resources. Because of the major role of non-healthcare factors – social, genetic, developmental and environmental (described in section 1.6) – in determining health, allocating healthcare resources with the aim of achieving equality of *health* across different regions is likely to lead to a highly unequal pattern of RA (453). In fact, because the effects of several of these factors are in practice irreversible, equality of health across regions is very unlikely ever to be achievable. This problem is exacerbated by the fact that important influences on health such as poverty, low educational achievement and environmental pollution tend to cluster geographically

(455), so that allocating healthcare resources among geographical regions with the aim of achieving equality of health among those regions becomes even more difficult.

In addition to this problem, use of the term "equality of health" implies that the magnitude of health can be measured in some way and that the magnitude of health of two individuals or of two groups of individuals can be compared. The use of numerical descriptors of self-assessed health state, such as the EuroQol scale (224) used in measurement of QALYs (section 2.4), offers a subjective assessment, summarised in a single number, of an individual's assessment of the magnitude of her own health. Because of the way in which the questions in the EuroQol scale are framed (456), however, the scale reflects the individual's *attitude* to her own state of health, rather than an objective *measure* of her health which could be compared with that of others. However, it could be said that a government or administration whose RA decisions were based on principles of justice or fairness (see section 7.12) would aim at vertical equity in provision of healthcare resources; that is, the best health states that can be achieved in all sub-groups (classified by age and sex, by geography, by disease and by magnitude of disadvantage) that can be achieved within the resources available.

7.6 Equity

The term "equity" is the normative counterpart of the descriptive term "equality", and "inequity" is the normative counterpart of the descriptive term "inequality". Thus, inequity is inequality that ought not (according to some ethical principle such as justice or fairness – see section 7.12)) to exist. Whitehead (1992) described equity in health as the "absence of socially unjust or unfair health disparities" and health inequities as "differences in health that are unnecessary, avoidable, unfair and unjust" (452, 457). Equity therefore incorporates the principles of fairness and justice (452, 458, 459). "Equity in health" therefore describes the equality in health and in the social determinants of health, such as family income, housing, education and healthcare, which should obtain in a fair and just world.

Why equity?

John Locke described, in the *Second Treatise of Government*, how in a notional state of nature all people are equal, but in a civil society they surrender their right to defend their own interests:

> … for hereby he [i.e. the individual person] authorizes the society, or which is all one, the legislative thereof, to make laws for him, as the public good of the society shall require; to the execution whereof, his own assistance (as to his own decrees) is due. And this puts men out of a state of nature into that of a common-wealth, by setting up a judge on earth, with

> authority to determine all the controversies, and redress the injuries that may happen to any member of the commonwealth. (258)

This means that government and public administration in a civil society depends on the consent of the governed, and that consent of an individual is given on the understanding that administration will be carried out in the interests of the community and that the consenting individual will be better off consenting to such an arrangement than fending for himself in a state of nature. As Rawls pointed out, a rational person, if he did not know where on the scale of advantage and disadvantage he was to be, would choose an arrangement whereby advantages were distributed fairly (459). According to this account of the social contract then, a rational person would be more likely to consent to be governed if the administration of his civil society distributed advantages fairly, and the administration of such a society should assume that its citizens have ceded to the administration their rights to defend their own interests on the understanding that advantages will be distributed fairly as far as it is in the administration's power to do so. Whitehead observed that "a national health policy which is intended to cater for the health needs of a whole population fails if it does not address the greater burden of illness found in the socio-economically disadvantaged" (460).

As already pointed out (section 1.5), the major contributors to ill-health are socio-economic and geographic, and the health consequences of disadvantage are severe. Disadvantaged people die younger and experience more chronic illness over their lifetime and starting at a younger age than more affluent groups. Their children have shorter stature and worse dental state than more affluent children (460). Rural people, including rural children, have a higher mortality rate corrected for age than their urban counterparts (460) (section 1.9). The greater the difference in economic state between rich and poor in a society, the worse is the health of those in the middle and lower socio-economic strata, and beyond a certain level of socio-economic inequality in a society, relative socio-economic status is a more important determinant of health than is absolute income (458).

Is inequality in all non-healthcare determinants of health inequitable?

Whitehead (1992) suggested that ill health due to some factors, such as genetic and developmental abnormalities, dangerous behaviours freely undertaken, and transient health advantages of one group over others is not inequitable. In contrast, the contribution of other factors such as exposure to dangerous or stressful living and working conditions, inadequate nutrition and damaging behaviour when lifestyle choice is limited (e.g. smoking and consuming alcohol when most others in the stressful and dangerous occupation are doing the same), is avoidable and therefore inequitable (460).

Horizontal equity and vertical equity

"Horizontal equity" refers to the precept that equal cases should be treated equally, while "vertical equity" refers to the precept that unequal cases should be treated unequally. In other words, to achieve vertical equity, a disproportionate amount of resources should be allocated to improve the welfare of disadvantaged groups. The distinction between those two concepts was made by Aristotle in the *Nicomachean Ethics* (461) and has been elaborated by others with specific reference to the allocation of healthcare resources (211, 453).

7.7 Prioritarian

In contrast with the various egalitarian views (see section 7.5) is the position which holds that some individuals or groups should be allocated more of a good than other groups. This more favourable allocation may be based on what each group deserves, or what each is felt to have earned by some action or other, or it may be a greater allocation of some good to the worse off group. As described below (section 7.12), John Rawls reasoned that a rational agent behind a veil of ignorance would, in her own interest and being unaware of her own real-world situation (including whether she is in the disadvantaged group), adopt the ("maximin" or "difference") principle that after equal rights to freedom are secured, goods should be distributed so as to maximise their distribution to the disadvantaged (45). Thomas Nagel pointed out that according to the difference principle, the value of improving the situation of the worse off has priority over improving that of the better off, regardless of how much the situation of each is improved by a distribution of goods, and regardless of how many people are involved (462).

Thomas Scanlon (1976) presented a similar argument, but suggested that the bad aspect of inequality (in welfare or in receipt of some good such as healthcare) is not just that the worse off individual has a low level of that good, but that others have more of it, especially if the amount of the good possessed by the better off is the norm for that society (463). Parfit, on the other hand, argued that, according to the priority view of justice in distribution of goods, what matters to the worse off individual is her *absolute* level of welfare, not the fact that others are better off than she is. Furthermore, he argued, distribution according to need is a form of that priority view (447). Parfit suggested that any moral position which requires the actor to make distributions which favour the worse off because they were worse off than others, is a deontic (see section 7.5) egalitarian position rather than a truly prioritarian one (447).

It has also been suggested that a prioritarian argument for distributing goods to the worst off on the grounds of their low absolute level of welfare might be based on compassion (see section 7.10).

Crisp pointed out that an impartial observer would only distribute goods preferentially to the worse off on the grounds of compassion if those worse off were truly badly off, so that there would, in this view, be an implicit threshold of wellbeing, above which the individual does not get priority, but below which she does. In other words, compassion would not justify distribution to the rich at the expense of the super-rich (464).

This argument, however, ignores the subjective and society-specific nature of compassion. The health outcomes of rural children in Australia are demonstrably worse than those of urban children in many respects (see section 1.8), and the access to healthcare of rural children in Australia is less than that of urban Australian children. For these reasons, rural children are deserving of our compassion and that of government healthcare allocation decision-makers. At the same time, rural children in Australia are considerably better off in terms of health outcomes and access to healthcare than are children in many other countries. Although infant mortality in remote and very remote Australia (6.0 per 1,000 live births in 2016) is more than twice that in Australian major cities (2.9) (465), it is equal to that of the US as a whole and lower than that in 142 of 193 countries surveyed by the World Bank in 2017 (466). So although from the viewpoint of an observer of international child health, rural children in Australia may not merit preferential allocation of healthcare resources, from the viewpoint of an Australian federal or state government observer who is dealing only with allocation of healthcare resources within Australia, rural children are considerably worse off than their urban counterparts, so there may be a compassion-based argument for preferential allocation of healthcare resources to them.

7.8 Rule of Rescue

The “Rule of Rescue” was first used by Jonsen (1986) to describe the imperative, felt by healthcare resource allocators, to assign a disproportionately large amount of resources to identifiable individuals who are at risk of imminent death, so that fewer resources are available to be distributed to the rest of the eligible population (467). This might be considered to be a subset of prioritarian RAs. An example of the Rule of Rescue is the (state-financed) supply of very expensive chemotherapeutic drugs (out of a limited health budget) to individuals dying of rare cancers (216). McKie and Richardson pointed out that this imperative is primarily a psychological one, motivated by compassion for a visible, identifiable fellow human in immediate mortal danger, rather than by ethical duty. They noted that identifiability is not a morally relevant attribute, but admitted that there may be a utilitarian justification for the Rule of Rescue in that members of a society “obtain benefit from the belief that they are living in a caring and humane society” when they perceive that

human life is so valued in the society that disproportionate efforts are made to save those in mortal danger (468).

Children living in rural and remote areas of Australia are known to have worse health outcomes than the rest of the child population, and might therefore be considered to be potential beneficiaries of the Rule of Rescue. McKie and Richardson argued, however, that those in the worst off category (such as rural children) are a statistical group rather than identifiable individuals, so that the Rule of Rescue does not apply to them (468). Furthermore, while the healthcare disadvantage of rural children may increase their risk of poorer health outcomes, that risk, shared by the whole group (rural children), does not elicit the same imperative to rescue as the imminence of death.

7.9 Communitarian

Communitarian ethics has a long history, from Aristotle and St Thomas Aquinas through to modern ethicists such as Daniel Callahan and the late Gavin Mooney (279, 469). Communitarianism remains an ill-defined ethical position with many variants, but its essential tenet is that while the focus of most liberal ethical positions – including consequentialist, rule-based, rights, justice and virtue ethics – is on ethical decision-making by the individual, a more coherent position is that of rule-making by the community. Some part of the ethical obligations of the individual consists of conformity with the rules and shared values of the communities of which she is part (279, 470). Amitai Etzioni, a leading figure among the professed communitarians in the US, described the defining characteristics of a community as

> ... a web of affect-laden relationships among a group of individuals, relationships that often crisscross and reinforce one another … And second, a measure of commitment to a set of shared values, norms and meanings, and a shared history and identity – in short, to a particular culture. (471)

Communitarians hold that it is only because we are part of a group (or community) that we are required to have any ethical position at all. If each of us were alone in the world, no ethical position would be required. It is only the presence of others that requires us to have ethical criteria by which to regulate those of our actions which affect them (470). Communitarians maintain that an ethical stance which ignores the fact that we are part of a community, and that being part of a community makes us who we are and modifies all that we do, is incoherent.

In fact, we are all part of multiple communities. For example, we are members of the communities of all living things; all humans; all humans living now; all humans living now in this country. Some of us are also members of the community of all rural people in this state. Each of our communities has

value and in turn, has its own ways of behaving and its own expectations of how its members should behave. From a liberal point of view, in which the interests and the duties of the individual are paramount, the only value and interests of families and other social groupings are the value and interests of the individuals who compose them. The family and the other social groups per se have no other value and no duty is owed to them other than that which is owed to their constituent individuals (470). Communitarians, on the other hand, argue that social groups such as the family have value in themselves, in addition to that of their constituent members, and the interests of the group per se must be taken into account when decisions are made which affect it (470).

The amount of autonomy and freedom of an individual to make her own ethical decisions that is possible in a communitarian system is a matter of debate among communitarians (471, 472). In Etzioni's description, the values of the community are not imposed on the individual; rather, the individual shares the set of core values of the community of which she is a member (471) and she retains autonomy; that bounded autonomy is "a range of legitimate options within an affirmed normative framework" (471), the normative framework being the shared values and ethical norms of the community. Gawkowska, on the other hand, claimed that:

> … if one treats the idea (of autonomy) seriously and defines it as the right to formulate one's own rules, free from any imposition, one experiences all kinds of pressure (such as moral pressure from the rest of the community) as coercive and illegitimate. (472)

The disagreement between the two viewpoints seems to derive from the fact that Etzioni is describing the situation that one can observe in the real world, while Gawkowska is noting the discrepancy between that observed situation and what would happen in a perfect liberal world.

In arguing for a communitarian approach to the allocation of healthcare, Callahan (1990) emphasised the difficulty for the individual of separating health needs from health wants (473) which are potentially limitless, so that "meeting all individual (health) need is neither possible as a reality nor plausible as a moral goal" (473). He argued that health has an individual dimension (in that ill health causes pain, suffering and limitation in one's ability to achieve one's life goals) (473) and a social dimension (in that every individual is part of a community and has a social role and a connection to others within that community) (473). Therefore, Callahan suggested

> The goal of the healthcare system should be that of helping us to meet our occupational and social roles and duties while, at the same time, helping us to live effectively within the interpersonal sphere of our lives within communities. (473)

Thus, “as a social system aiming at the cure of illness and the forestalling of death, the healthcare system should give priority (though not exclusivity) to its societal needs, not to the needs of individuals” (473). It should be remembered though, that Callahan was arguing against the liberal position that each individual is responsible for his or her own health and for supplying his or her own healthcare needs. He was not arguing against the Rawlsian view (see section 7.12) that extra benefit should be accorded to the disadvantaged (such as, in Australia, rural children).

Hub Zwart (1993) contrasted the liberal view of healthcare – a medical treatment is basic and necessary if it is required to meet a need of the individual to allow him to function according to his wishes – with the communitarian view – a medical treatment is basic and necessary if “it enables an individual to share, maintain and if possible improve his life as a member of the community” (280). According to the latter view, the aim of healthcare being to permit an individual to be part of a community is determined by the community, not by the individual, and the healthcare preferences of individuals should not be given priority over those of the community (280).

Mooney, in several publications, emphasised the aspect of respect on the part of the wider community for sub-communities and their needs and values (279, 281, 474) in the allocation of healthcare resources to those communities. Mooney pointed out that when healthcare resources are allocated according to a strictly liberal view of individual need, the values of the community that the healthcare resources are intended to serve are insufficiently taken into account when those “needs” are defined (281). Respect for sub-communities means respect for the autonomy of the sub-community and for its values. This means respecting the collective rules, made at community level and based on education of the community, about what are appropriate health goals and therefore what are appropriate health needs to achieve those goals (474). The example that Mooney used was the Australian Aboriginal community and the way in which vertical equity (see section 7.6) in healthcare RA might be achieved among Australian sub-communities (279, 474).

7.10 Compassion

Compassion is an emotion which motivates actions, including the making of moral choices. It has been defined as “the feeling that arises in witnessing another’s suffering and that motivates a subsequent desire to help” (475). In the context of the present study, the term “suffering” might be replaced with “significant disadvantage”. Compassion has also been defined as “a painful emotion occasioned by the awareness of another person’s undeserved misfortune” (476). Nussbaum distinguished between “compassion”, with its implication of motivation for action, and “pity” which now carries implications of condescension and superiority to the person(s) pitied, and “empathy”, which implies vicarious experience of another’s suffering but without necessarily motivating action

to relieve the suffering (476). Amartya Sen made a distinction between "sympathy" (a vicariously experienced emotion which does not necessarily motivate corrective action) and "commitment" (an understanding of the wrongness of a situation which affects another person without making the observer personally worse off, but which motivates the observer to take action to improve the situation and reduce the suffering or disadvantage of the sufferer) (477). Snow (1991) emphasised the role of altruism in compassion, defining compassion as "'suffering with' another, that includes an altruistic concern for the other's good" (478).

Anthropological studies have traced the evolution of compassion from non-human primates via pre-industrial cultures to modern Western societies (475). Gintis noted that there is a tendency in all successful societies for cultural institutions to promote pro-social norms such as compassion and altruism and to discourage antisocial norms, because societies that promote pro-social norms have higher survival rates than those that do not. These norms, he suggested, are internalised by individuals and acted upon, even when those actions don't promote the survival of the individual (479).

What is required to elicit the emotion of compassion?

To elicit compassion requires, first, a perception that a person with whom one has some characteristics in common, such as humanity, culture, possibilities for the future, and vulnerability, is suffering some harm or at least some disadvantage. Second, that the harm or disadvantage is serious, and third that the harm or disadvantage was not caused by some blameworthy action of the sufferer herself (480). It is commonly observed that the closer (in kinship, culture or geography) the sufferer is to the observer, the more likely is suffering to elicit compassion (464, 476). Nussbaum suggested that "the pain of another will be an object of my concern only if I acknowledge some sort of community between myself and the other, understanding what it might be for me to face such pain" (480).

Compassion as motivation for moral action

The role of emotions, including compassion, as motivators of moral judgements has long been disputed. Kant, for example, rejected sympathy as a motivation for making moral choices, regarding a predisposition to sympathy as "weak and … always blind," precluding its motivating actions that are consistent with justice (206). Others have disputed this view, however: Goetz et al. (2010) suggested that emotions (including compassion) act as intuitive judgements of right and wrong actions, and that "compassion motivates moral judgment and action (about) unjustified harm" (475). There is some empirical evidence for this view: Batson and Shaw (1991) summarised the results of 20 human experiments, each of which demonstrated a link between "empathy" (a term used by

Batson, meaning the same as Nussbaum's "compassion") experienced by an observer and altruism-induced helping behaviour (481).

Crisp (2003) suggested that a truly virtuous arbiter of RA would be more concerned for the welfare of the badly off than for those better off, and, motivated by compassion, would act to allocate resources so as to improve their lot (464). This argument relies on his (and by implication, our) intuition that compassion is a virtue and impartiality is a vice. Crisp further suggested that such a compassionate arbiter would be able to identify a threshold of inequality among potential recipients, above which resources should be allocated disproportionately to the worse off, and below which no such priority in allocation is given (464).

Amartya Sen (1977) produced a detailed argument that "commitment" (see section 2.7 above) can motivate moral actions which benefit an observed sufferer, even when those actions do not further, and may even impede, the best interests (direct or indirect) of the benefactor (477). He was arguing against the mainstream economic view that the motivation of all choices is self-interest, and even moral choices which appear to be altruistic are in fact motivated by a "warm inner glow" felt by the actor who makes a moral choice which benefits another person. According to mainstream economics, an "altruistic" person benefits from performing acts which benefit another, because they value the welfare of the other, or charitable actions in general, and so gain pleasure from their own generosity (482, 483).

Compassion and the promotion of capabilities

Nussbaum argued that a society, its laws, institutions and principles of distribution can and should operate by the rules of compassion for individuals, taking into account the seriousness of harm (or disadvantage), the individual's level of responsibility for the harm, and some definition of the limits (for whom and about what) the society should show compassionate concern for its members. Taking the argument further, Nussbaum suggested that what the compassionate society should guarantee to its members are the capabilities that are needed to maximally fulfil one's possibilities (476).

The idea that the concept of capabilities is basic in any list of human goods has a long history, but has been developed most clearly by Amartya Sen (194) and Martha Nussbaum (476). "Capability" here refers to "the opportunity to achieve valuable combinations of human functionings – what a person is able to do or be" (484). That is, whether someone "possesses the means and instruments and permissions to pursue what she would like to do" (484) rather than whether she actually does it, which might depend on irremediable circumstances such as congenital disabilities, geography or her relationship to others. Sen suggested that basic capabilities might include the ability to move about, the ability to be adequately fed, clothed and sheltered and to participate in the social life of the

community (194). Nussbaum's list of the capabilities which a society should provide for its citizens was rather more specific and comprehensive, though the weight accorded to each must vary with the circumstances of the individual and of the society (484):

- a life of normal length and of a quality worth living;
- ability to have good health, adequate nutrition and shelter;
- ability to move about freely and safe from violence;
- ability to use one's senses, imagination and reasoning;
- ability to form emotional attachments to things and people, unimpeded by fear and anxiety;
- ability to form one's own concept of the good;
- ability participate in social interaction, to live with and experience and show concern for others;
- ability to play and laugh;
- ability and right to participate in political choice and to enjoy freedom of speech and association; and
- ability to own property, to work and associate with fellow workers, to be free from unwarranted search and seizure. (476)

In Sen's view, the concept of capabilities emphasises the opportunity to have these things. Each individual is free to avail themselves of this opportunity or not (484).

Compassion as the basis for contractarian systems of ethics

The most widely accepted theories of a social contract as the basis of interpersonal relations and the relations between individuals and the state are variants of Thomas Hobbes' postulate of rational agreements between weak but autonomous, self-interested individuals (139). Snow (1991) suggested that rationality in a social contract did not require self-interest as the only possible motivating force, but rather that "any action, desire or emotion that accords with an agent's justified beliefs is rational for that agent" (478). Compassion, for example, if based on justified beliefs, could rationally justify actions to benefit another, even if that action did not serve the best interests of the actor. Thus, whereas in Hobbes' social contract, all others are potential enemies, and cooperation is only maintained by the enlightened self-interest of all, Snow suggested that awareness of the weakness, vulnerability and liability to misfortune of oneself and others, combined with compassion towards others, means that each views the others as potential sources of aid in the case of misfortune: "one way to increase one's chances of receiving compassion from others is to be compassionate oneself" (478).

It could be argued that since experiencing compassion requires recognition of commonalities of situation, vulnerability and possibilities that one shares with the sufferer, in acting to relieve the suffering one is giving a benefit because of awareness that one may require the same benefits oneself one day. However, Nussbaum denied such a contractarian view; she claimed that

> the compassionate person remains fully aware of the distinction between her own life and that of the sufferer, and seeks the good of the sufferer as a separate person, whom she has made a part of her own scheme of goals and ends. (476)

This view of non-self-serving compassion is not incompatible with a compassion-based social contract, however: even when norms of behaviour are guided by a compassion-based social contract, some completely altruistic actions are possible.

Compassion as the basis of solidarity

Matti Häyry (2005) pointed out that "sympathy, universal benevolence (by which he referred to utilitarian benevolence) and justice do not always prompt us to do good to specific human beings" (485). According to his account, sympathy fails because it does not necessarily lead to action; universal benevolence can fail the individual in favour of the greatest good for the greatest number; justice, understood as the protection of individually defined rights, may or may not benefit the suffering individual if that individual's rights conflict with those of others (485). Whereas in anglophone countries such as the UK, US, Canada, Australia and New Zealand, justice and equity are the goals of healthcare RA, in the welfare state health systems of continental European countries such as the Netherlands, Germany and Poland, solidarity is the guiding principle (485-487). While justice and equity focus on the interests of the individual, solidarity emphasises social interdependence, leading to "mutual respect, personal support and commitment to a common cause" (486). Solidarity seen in this way has much in common with communitarianism.

Apart from this institutional meaning of the term, ter Meulen pointed out that solidarity refers, at an individual level, to altruistic concern for a fellow human being who is suffering or in need, and to a general fellow-feeling for the disadvantaged in society. This motivates action to protect those who are suffering or disadvantaged undeservedly because of congenital illness or socioeconomic or environmental disadvantage (486). There is a clear similarity of this account of solidarity to Nussbaum's account (described above) of compassion and its role in motivating moral actions. Zabdyr-Jamroz made this similarity explicit by defining "compassion solidarity" as "a type of cooperation that is based on reciprocal willingness to provide assistance to those in need" (488).

This particular concern for the disadvantaged has much in common with what Gavin Mooney described as “vertical equity” (453) (see section 7.6), although in Mooney’s account, the emphasis is still on the interests of the disadvantaged individual rather than on the collective way in which individuals in a society respond to others.

Compassion, solidarity and justice

Wim van Oorschot (2006) described the change in the meta-ethical basis of the Dutch social security system between the 1960s and the early 2000s (489). The guiding principle in the 1960s was that “every citizen has a right to self-realisation and to equality of chances” and emphasised the responsibility of every citizen for each other’s chances of having a good life. Changes in the political and economic climate in the next 40 years, however, led to a gradual evolution of those underlying principles, such that by 2004, the emphasis was on personal responsibility for one’s own welfare, with reduced concern and expenditure on the part of the state (489). This represents a shift from cooperation and compassion and community-based concern and responsibility for one’s fellow citizens to a principle based on individual self-interest, and in case of severe need, on justice and equity.

Ruud ter Meulen, contrasting the role of the state, governed according to principles of solidarity, with that guided by justice and equity, portrayed liberal theories of justice as emphasising the right as opposed to the good. According to this view, the role of the state and of the society is not to maximise the good life for its citizens, but rather to enable individuals to enact their own life plans by treating them as far as possible with justice and equity. He concludes that the gradual shift in the principles guiding state provision of health and social care “may result in an impoverishment of the relations in health care which are fundamentally based on benevolence and commitment to the well-being of the other” (486).

Daniel Batson described the opposition of the two principles from a different viewpoint, pointing out that while altruism and compassion may motivate a desire to support the principle of justice, acting on compassionate feelings may lead one to act against the principle of justice. He reported the results of two experiments in which participants who felt empathy for a disadvantaged individual were more likely to favour the interests of that individual, and distribute benefits in a way that was contrary to the principle of justice, than participants who did not feel compassion (490).

Compassion as a guide to behaviour of public institutions

As described in the previous section, solidarity based on mutuality and compassion for disadvantaged individuals has been a guiding principle for the allocation of welfare and healthcare resources in countries of continental Europe. Martha Nussbaum has advocated its more universal use, including in Anglophone countries, where currently principles based on individual self-interest hold sway: "compassion can and should inform the structure of public institutions themselves, so that we do not need in every case to rely on the perfect compassion of individual actors" (480).

Compassion, operating at the level of government institutions, appears to be the principle which motivates the Rule of Rescue (see section 7.8). The allocation of funds to identified groups of patients (e.g. for very expensive drugs to treat rare conditions) in an effort to rescue them from severe harm is an explicit policy of the Australian PBAC, though it appears not to conform to any moral principle, and by using limited resources in the interests of only a few patients, may limit the improvement in health of the whole community that could be delivered by spending the same amount of money on disease prevention, for example (see section 1.8) (491, 492).

7.11 Rights

The concept of rights, as it is understood today, dates from the 17th century in the writings of Hugo Grotius (493) and Thomas Hobbes (139), who first wrote of the right of an individual or a state or its sovereign (493) to act in a certain way or to be in a certain way (494). The concept of rights and the human concerns to which rights might apply were elaborated and expanded by, notably by John Locke (258) and Thomas Paine (495). Although the idea of rights, innate in man, was one of the inspirations of the French and American revolutions, the concept fell into disfavour in the 19th and early 20th century. Rights as a universal attribute became prominent again after World War II, with the Universal Declaration of Human Rights (260) and the Declaration of the Rights of the Child (415).

What are rights?

Rights are things to which an individual or group of individuals is entitled. One may be entitled to do something or not to do it, or to be in some state or not. One may also have a right that others do something or refrain from doing it (496). The general structure of rights can be expressed by the formula: *A has a right to X against B because of Y*

Where A is the bearer of the right, B is the person or group that has a duty to satisfy the right, X is the thing to which A is entitled, and Y is the justification for the right (497).

Wesley Hohfeld (1913) described four basic aspects of rights (498):

- **claims**: A has a claim that B will perform action X. This means that B has a duty to A to perform action X. For example, a child (A) has a claim-right that her parent (B) will feed her. The parent therefore has a duty to feed the child. Claims may be against a particular individual (e.g. the parent), against an organisation such as a department of health, or against an undefined number of people (e.g. if a child has a claim-right not to be attacked on the way to school, that claim is against all other persons (496, 498)). The claim may thus be positive (to do something) or negative (to not do something);
- **privileges**: A has a privilege to do action X if A does not have a duty not to do X (496, 498). For example, a parent may be said to have a privilege-right to make healthcare decisions on behalf of his child. Some privilege-rights exist because of some specific licence (e.g. a licence to practise medicine) or because the privilege holder occupies some office (e.g. a policeman in Australia has the privilege-right to carry a firearm), while other privilege-rights exist even in the absence of a specific licence or office (e.g. a child may (i.e. has a privilege-right to) tie her own shoelaces);
- **powers**: A is said to have a power-right if A is able to alter her own or someone else's claim or privilege (496, 498). For example, a department of health promises to vaccinate all infants in its region against polio; this creates a new duty for itself to vaccinate all infants in its region against polio, and thereby creates a new claim-right of all infants in its region to be vaccinated. The health department can be said to have the power-right to make that promise; and
- **immunities**: A is said to have an immunity-right if B lacks the power to alter A's claims or privileges (496, 498). For example, an 18-year-old has an immunity-right against her parent if the parent lacks the power to alter the 18-year-old's claim to make her own healthcare decisions.

According to J. S. Mill, "When we call anything a person's right, we mean that he has a valid claim on society to protect him in the possession of it, either by the force of law, or by that of education or opinion" (439). Rights may be "perfect" (i.e. enforceable) or "imperfect" (non-enforceable) (493). Enforceable rights include those that are stipulated by laws and backed up by legal sanction. Cranston (1983) (499) categorised rights as follows.

- *general positive legal rights* which are held by all persons living under a particular jurisdiction;
- *nominal legal rights* which exist on paper but in practice are denied by the ruler or the state;

- *positive legal rights of specific classes of persons* (e.g. police officers, members of parliament, medical practitioners); and
- *positive legal rights of a single person* (e.g. the Queen of England).

In each of these cases, one can ascertain the possession of the right by examining the law in which it is stipulated. Moral rights on the other hand, are not stipulated by laws, and "can only be established by appeal to moral principles or to natural law" (499). For example:

- *moral rights of a single person*, who has earned those rights by having done particular work, fulfilled a particular role or office, or paid a fee;
- *moral rights of specific groups of people*, such as parents or those who care for aged or disabled relatives. These moral rights arguably exist, in virtue of the responsibility borne by the parent or carer for the welfare of the incompetent child or relative. These rights can be overridden by other parties, including the state (See below: "Imperfect rights"); and
- *human rights* (See below: "natural rights"). These are rights possessed by all persons at all times, simply because they are human.

What do rights do?

The function of rights is the subject of considerable dispute. Some consider that their purpose is to impose a corresponding duty on someone, while others believe that their purpose is to advance the interests of the rights-holder (496). Sreenivasan has suggested that possession of a right imposes just enough duty on another person (or persons) as is necessary to advance the interests of the rights-holder (500). Wenar described claim rights as "conclusive reasons": if A has a claim-right that B do X, then that gives B a conclusive reason to do X (496). However some rights have priority over others, and some non-rights considerations have priority over some rights, so that a right is only a *conclusive* reason in a certain specific set of circumstances (496). For example, when the right of a child to obtain optimal healthcare conflicts with that of a parent to keep her job and so support the family, the exact family circumstances will determine which right has priority.

Nozick (437) and subsequently Scanlon (501) have characterised rights as "constraints on the discretion of individuals or institutions to act" (501) which avoid injury to the interests or freedoms of the rights-holder. L. W. Sumner proposed a hybrid moral theory, in which rights exist as constraints on the free pursuit of consequentialist goals. The effect of these rights-based constraints is to protect the interests of individuals. These rights are "protected choices" of a rights-holder, each of which has specific "existence conditions" (i.e. things that have to be present for there to be a right) (502), such that not just anything can be claimed as a right.

Rights have been described as having "thresholds" which determine the order of priority when the rights of others, or non-rights considerations compete (503). The threshold of a right depends on the seriousness and urgency of the harm which would be caused by its non-observance (e.g. one individual's right to survival or to freedom might trump another's right to exclusive use of property (503)) and the feasibility of fulfilling the corresponding duty (e.g. a child's right to be taken to a hospital for optimal healthcare today may not reach the threshold if her parent cannot obtain transport to take her there).

How are rights justified?

The three main arguments for the existence of rights are those of respect for an individual, rights as means to some desired end, and arguments from social contract (496). The *deontological argument*, of which John Locke was a prominent early exponent (258), proposes that every man possesses some rights over his own person and that these rights are ascertainable by reason alone. All humans, this theory suggests, possess those rights by virtue of the fact that they are human ("the source of human rights is man's moral nature" (504)), rather than because they have needs (see section 2.4) which bestow rights to have those needs satisfied. That is, humans possess those rights which are needed to enable them to function as moral agents. This is the *agency* account of rights. Amartya Sen on the other hand, suggested that persons possess rights because they have claims to certain freedoms which, in turn, are opportunities to achieve combinations of functionings that are important to them and which others regard as important (505). He suggested further that the exact rights which persons possess are ascertainable by public debate rather than by introspection or by reason alone(505). This is the *welfare* account of human rights.

The *utilitarian* justification of rights proposes that a right is justified if possession of that right (with the duties that are thereby imposed on others) brings about the greatest combination of good outcomes. Jeremy Bentham expressed this net benefit as advantage to society:

> … there is no right which ought not to be maintained so long as it is upon the whole advantageous to the society that it be maintained, so there is no right which, when the abolition of it is advantageous to society, should not be abolished. (506)

This view of rights reduces to a form of rule consequentialism (see section 7.4), which makes the concept of a right almost redundant, and greatly weakens the claim held by an individual, if the best overall outcomes were to be achieved by disregarding that individual's claim (496). Wenar points out that not all consequentialist arguments for rights are utilitarian; an argument for egalitarian rights, for example, would recognise rights, the enactment of which would lead to equality in some

characteristic, between persons. An argument for prioritarian rights would assign rights preferentially to some group (e.g. rural dwellers, the young, the socially disadvantaged) (496).

Rights can also be seen as existing within a particular society only insofar as the members of that society agree on their existence. This *contractarian* view has a long history, dating at least as far back as Hobbes: "The mutual transferring of right is that which men call contract" (139). More recently, John Rawls proposed that all persons possessed equally some fundamental claims. These include liberty of the person and of conscience, and freedoms of speech and of association and rights to vote and to hold public office. Rawls (459) suggested that these claim-rights are those that a rational person would want for herself and therefore for all others, if she were in the hypothetical position of unawareness of her own age, gender, race, class, socioeconomic status or natural endowments (i.e. if she were behind the veil of ignorance (see section 7.12)). L. W. Sumner argued that if there are any objective goods (i.e. things that are objectively good), then there must be objective (i.e. non contractual) rights, but that the existence of objective goods is very difficult to prove or disprove. This leaves open the question of the validity of the contractarian view of rights (502).

Natural rights

These are rights which all human persons possess by virtue of the fact that they are human. It has been argued that if one has a need (see section 2.4) for something, then that need gives one a claim against all other persons and institutions to have that need satisfied (507). The strength of the claim depends on the importance of the need. Based on Bay's argument that self-respect is needed for moral agency and is therefore a human right (507), Donnelly argued that natural rights (also known as human rights (504, 508)) are rights which we possess to all things that we need in order to be moral agents (504). Amartya Sen based his argument for the existence of universal human rights on claims to freedoms: these are opportunities to achieve combinations of functionings that are important to the person (505).

Early formulations of natural rights and their contents specified only a few basic rights. John Locke, for example, suggested that the only natural rights were the rights of possession of one's own person, one's labour and the fruits of one's labour; the right to sustenance ("meat and drink and such other things as Nature affords for their subsistence" (258)), the right not to be harmed by another and the right to punish transgressors with the aim of preventing future transgression (258). H. L. A. Hart in 1955 argued that if there were any moral rights at all, there was "at least one natural right, the equal right of all men to be free", by which he meant free from coercion or restraint and free to perform any action which did not coerce, restrain or harm another (509). In the second flowering of human rights in the second half of the 20th century, however, a much greater number of

things were described as human rights (and by implication possessed by all persons in all situations). The Universal Declaration of Human Rights, adopted in 1948 by the United Nations General Assembly, has 30 Articles, stipulating rights which range from the right to life, liberty and security of person (Article 3), to rights to work and to "just and favourable" working conditions, with "protection against unemployment" (Article 23) and "reasonable limitations of working hours and periodic holidays with pay" (Article 24) (260). These "second generation rights" to social goods (494) have been described as the rights that people ought to have rather than rights that they actually possess (510).

The concept of rights has been criticised by a variety of authors, from Jeremy Bentham (506) to Mahathir Mohamad (511), and criticisms have ranged from attacks on the nature of rights sentences ("a reason for wishing that a certain right were established, is not that right" (506)) and on the means by which rights are ascertainable (512) to questions of the extent to which the rights concept applies in non-Western communities (511) and of the ill effects of rights discourse on the observance of civic duties and on our idea of ourselves as members of a community (513). Sumner (1957) pointed out that in many issues in which an appeal is made to some claimed right, an opposing claim could be made by an appeal to some other claimed right. For example, the right of a woman to determine what happens to her own body is opposed, in debates about induced abortion, by claims on behalf of the foetus, of its right to life (502). Sumner described the multiplicity of such claims, often found in "claims manifestos" (502), made by bodies which do not pretend to be able to enforce these claimed rights. These manifestos include the Universal Declaration of Human Rights (260) and the UN Convention on the Rights of the Child (415). Both of these documents set out a catalogue of claimed rights which resemble aspirations rather than observations. Certainly, many of the claimed rights do not reflect the life experience of persons or of children in many countries in the world today or in the past.

The language of rights

The nature of the language used in these manifestos to describe these rights claims appears to be more in the imperative mood than in the indicative mood. That is, a claimed right is something that the promulgator of the claims manifesto wishes us to recognise, rather than something that has an objective existence. Thus, a statement in the UN Convention on the Rights of the Child states that "No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence" (415) means in effect "*let* no child be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence." This interpretation of rights

statements as commands is analogous to R. M. Hare's view of morals statements in general as universal prescriptive statements (514).

Children's rights

What is a child? The UN Convention on the Rights of the Child defines a child as "every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier" (415). While in the past children were regarded as the property of their parents ("one's property or offspring (until the latter is of a certain age and independent) is like a part of oneself" (461)) or like an aspect of their parents (515), they are regarded today as morally separate entities, albeit with moral characteristics different from those of adults (516).

Brighouse pointed out that there are two major classes of rights: welfare rights and agency rights. He argued that while infants and very young children are not capable of being moral agents and are therefore not possessors of agency rights, they do possess welfare rights (517) (see section 8.12). Infants and very young children do not have the experience, the understanding or the physical capacity to make moral choices and so to be moral agents, but they have the potential to become moral agents and to make moral choices in the future (518). Although one of the preconditions needed to be a possessor of rights is to be a moral agent (423, 504), Griffin suggested that "if agency is so specially valuable, then some of that value must get transferred to what is a necessary condition for it" (518). That is, if an infant is to become a moral agent, that infant must have at least some rights, including the rights to life, nutrition and protection from harm, to enable her to develop into a moral agent. On the other hand, Griffin pointed out, this argument could also be applied to zygotes, foetuses and embryos, which are not generally regarded as having rights. Griffin's conclusion was that while infants do not possess rights, children acquire rights in stages as they acquire agency (518).

As children grow older and their experience and understanding of the world increases, they progressively gain agency and the ability to make moral choices, and therefore progressively gain the rights to those things which will enable them to function as moral agents. According to Brennan though, moral choices made by children as they develop into moral agents, are frequently unstable. A child may make one choice one day, and the opposite choice the next, though the circumstances in which the choice is made remain unchanged (519). This instability, according to Brennan, limits the claim even of older children and younger adolescents to possession of agency-based rights. Brighouse argued though, that future agency interests are not different in kind from present agency interests, and that the interest of a child in becoming a moral agent in the future justifies her

possession, throughout childhood, of similar (though not identical) rights to those possessed by an adult (517).

During infancy and early childhood, children are vulnerable and dependent on others to supply their physical, educational and emotional needs (517) and their healthcare needs. Murphy (1977) argued that children possess rights on social contract grounds: if a Rawls "rational agent" (45) behind a veil of ignorance knew that he could be born as a child, he would wish that children should possess rights at least to some minimum standard of security and education (520). Brennan and Noggle suggested that

> … even quite young children are persons; they have identities, histories, and personal attachments. These are the kinds of things that are constitutive of humanity … (which) requires us to treat children as persons and accord them the moral status that other persons have. (521)

They did not feel, however, that this entailed according children the same rights as adults, because the adult role carries with it the rights to those things that are needed to fulfil that role. In their account, a child shares some basic human rights with the adult (such as the right not to be killed or harmed) but possesses a package of rights, specific to childhood (such as the right to education or to be fed and "to develop the capacities to satisfy her own needs and exercise her own rights" (521).

The child's best interests

It is accepted in most societies, and reflected in their laws, that when actions are taken which affect a child, the best interests of the child should be considered (516). This is reflected in Article 3.1 of the UN Convention on the Rights of the Child: "In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration" (415). Archard (2002) pointed out, first, that this principle requires that the best possible be done for the child, not merely an action that is good enough, and second, that the best interest principle applies to all children affected, so that competing interests of other children such as siblings and of adults must also be taken into account (516). Thus, the best interest principle cannot require an adult to sacrifice all her own interests to those of a child, provided that her parental duties are adequately performed (141). Archard argued though, that if one child is affected more by a decision than others, then that child's interests should receive more weight than those of children who are less affected (516).

Children's liberation

In the 1970s, a movement of children's liberation arose as an offshoot of the women's liberation movement. Children's liberationists argued that as children are persons, they therefore possess the same rights as adults ("today paternalism is out. It has been thoroughly discredited"), including rights to earn and keep their earnings and to "seek and obtain medical care and treatment and counselling" (522). This view was regarded as extreme and counterintuitive by other authors (516, 517, 523) and rejected, on justice and instrumental grounds, as being contrary to the interests of children and of society (523).

Imperfect rights

Onora O'Neill argued that our obligations to children are primary, and such rights as individual children possess are correlative to those obligations (524). In many societies, as Blustein pointed out, these obligations are stipulated in law (141), conferring correlative positive rights on the child. Further, O'Neill suggested, there are some obligations which adults possess, vis à vis children, which do not confer a correlative right on a child or children (524). She argued that adults have an obligation "to be kind and considerate in dealing with children – to care for them – and to put ourselves out in ways that differ from those in which we must put ourselves out for adults" (524). This incomplete obligation does not confer any right on any particular child (524). Unless these obligations (including, for example, general care for children, provision for their education and help in developing their potential) are codified (in law), no rights holders are identified, but we "have reason to construct and support institutions that realize and foster the discharge of these obligations" (524).

This latter consideration is relevant to the question of who is the agent against whom children's rights are held. That is, who holds these obligations? Some rights, such as the right not to be killed or harmed, are held against all other persons. Some positive rights of children (those specified in law in particular jurisdictions) are held against the state; these might include the right to at least a basic education, and the right to some level of healthcare. The provision of some other things that children need and ought to receive (such as kind treatment and encouragement to develop their talents), without their having definite rights to them, as O'Neill pointed out, is an imperfect obligation of all persons whose actions affect the child, but not a perfect obligation of anyone (524).

Duties of the state towards its citizens

Strict libertarians maintain that the only rights which the individual holds against the state are immunity rights (see above: "What are rights") against interference by the state with one's life or

personal freedom, and therefore the only duty of the state towards its citizens is to avoid harming them or obstructing their projects and to protect them from harm by others. Isaiah Berlin defined political liberty as "the area within which a man can act unobstructed by others" (525). According to this libertarian view, there are no such things as positive (socio-economic) rights such as the right to education or to some level of healthcare. These things, according to libertarians, are not rights, but rather, matters to be determined by the democratic process, and legislated (or not) by the elected representatives of the people (526).

Berlin also asked "What is freedom to those who cannot make use of it? Without adequate conditions for the use of freedom, what is the value of freedom?" (525) Pursuing this line of argument (though not the rest of Berlin's libertarian thesis), and accepting Amartya Sen's conception of freedom as opportunities to achieve things that one values (527), Fredman argued that freedom is agency; that is, freedom means the ability to be and to act according to one's life plan (511). To have this ability, according to Fredman, means to possess those things (such as health, education, housing and nutrition) which one needs in order to be able to act fully according to one's life plan. Furthermore, she argued, to have a right to freedom means to have a claim right to those necessary conditions for agency (526). Given the agreed duty of the state to act so as to promote the freedom of its citizens, those citizens have then, according to Fredman, a *prima facie* claim right to receive from the state as much of those things (such as education, healthcare, housing and nutrition) as they need, in order to become and remain, agents (526).

This argument, on the duty of the state to supply as much healthcare to each citizen as is needed to promote that citizen's agency, extends to the domain of rights the arguments of Sen, Anand and Daniels (144, 261, 528) on the moral importance of the provision of healthcare to individuals, on the grounds of the critical role of healthcare in maintaining the capabilities of those individuals (see section 1.7). According to this argument then, this duty of the state confers on each citizen of the state, adult or child, a correlative claim right to receive that amount of healthcare which she needs to maintain agency (in the case of an adult) or to develop agency (in the case of a child).

7.12 Distributive justice

The term "distributive justice" has been used to describe a variety of ethical principles which could be used to guide the allocation of benefits and harms (or burdens) to members of a population (454). These principles include strict egalitarianism (section 7.5), utilitarianism (section 7.4) and libertarianism (section 7.2). However, the discussion in this section is limited to justice as fairness (459) and the role (if any) of justice in the presence of bad luck. In its justification, the latter can be seen as a derivative of the former (45, 529).

John Rawls based his "ideal theory" of justice as fairness on the liberal conception of the self-interest of the individual. These "ideal" individuals are free, equal from a moral point of view, and rational, living in a stable society in which there are sufficient resources to meet the basic needs of all (417). Rawls postulated that there are certain basic goods "which it is supposed a rational man wants whatever else he wants" (45): these are those things which he needs to make and carry out his life plan according to his conception of the good, and might include basic rights to life and to protection from harm, freedom of movement and of choice of occupation, sufficient income and the social conditions conducive to self-respect (417). Rawls proposed that if a reasonable and rational person, behind a veil of ignorance (such that he was aware of the nature of the society but was unaware of his own age, gender, race, socio-economic position or conception of the good), were to decide on principles to guide the allocation of goods, he would select, in his own interests, principles of fairness. Rawls described the hypothetical circumstances in which these principles were to be selected as the "original position" (45). The two principles that, according to Rawls, it would be rational to select are, in order of priority (45):

1. That each person should have an equal right to as much freedom as is compatible with a similar amount of freedom for others.
2. a. The distribution of social and economic inequalities is to everyone's advantage and b. Those social and economic goods (which are distributed) are attached to positions and offices that are available to all.

Principle 2 (the "maximin" principle) (45) means that although inequalities in the possession of goods may remain after distribution, goods will be distributed so as to maximise their distribution to the least advantaged. This does not necessarily mean that differences in advantage between the best off and the worst off will be eliminated, or even reduced, but rather that if one is choosing between several patterns of distribution of goods, one should choose the pattern which leaves the worst off in a more favourable position than any other possible distribution patterns would. That is, principle 2 aims to produce the best *absolute* outcome for the worst-off, not the best *relative* outcome. This "difference principle" can be compared with the strict egalitarian approach to distributive justice, which demands that equal amounts of resources are allocated to each individual. That approach regards the situation of each person relative to the others as the important consideration, rather than the absolute situation of any, including that of the worst off (454). In the case of healthcare RA, however, the effects (of such a distribution) being considered are not a matter of being able to afford luxuries (or not) after monetary resources or advantages are

distributed, but the much more significant outcome of dying sooner or having a more impaired quality of life because of ill health.

Rawls pointed out, first, that the principles should guide distributive decisions by institutions and by the society as a whole, and second, that the intention of principle 2 is to improve the circumstances of persons who are disadvantaged by pre-existing "morally arbitrary" (45) circumstances such as age, parentage, social class, poverty and geography (45).

These prior contingent disadvantages can be seen as the result of bad luck rather than something over which the individual could have had some control. In the case of rural children, these morally arbitrary circumstances might include living in a remote area, or being born into an impecunious family, or into a family whose work commitments make travel to reach healthcare for the child difficult. Clearly these circumstances were not within the child's control, and any disadvantage suffered by the child because of them was not due to some action of the child.

As Arneson (2001) noted, whether one accepts that a pre-existing disadvantage (such as poverty or living in a geographically remote area) that was acquired by bad luck should be compensated to some extent by some pattern of RA depends on the moral principles that one accepts (530). A strict libertarian like Robert Nozick (423) would regard the fact that pre-existing disadvantage was or was not acquired by bad luck, or was or was not deserved, as irrelevant to the justice of any pattern of RA. Similarly, a utilitarian would regard the bad luck origin of disadvantage as morally relevant only if taking it into account in decision-making about an action produced a better overall outcome than not doing so. If one accepts Rawls' postulate of the principles which it would be rational to adopt if one were behind the hypothetical veil of ignorance, however, then a rational agent who aimed to protect her own possible interests, and who was confident that others would act reciprocally, would indeed decide upon a general rule for action which would deliver more advantage to those disadvantaged by ill-luck.

Criticism of Rawls' conception of justice as fairness

Rawls' social contract theory, though widely respected as a major contribution to the theory of justice (see Nozick, *Anarchy, state and utopia*, p. 183 (423)) has attracted criticism from many sides(531). Nozick, expressing the libertarian view that regard should be paid to antecedent deserved advantage (such as earned wealth), argued that Rawls' thought experiment of the rational agent selecting principles from behind the veil of ignorance, first, assumes unreasonably that fairness should be a guiding principle in RA and second, would inevitably select "end-state" principles (that is, principles which would pay insufficient regard to deserved advantage or disadvantage which exists before the allocation) (423).

From the communitarian side has come criticism of the individualistic assumptions behind Rawls' method of selecting principles of distribution; that is, of his assumption that a rational agent behind a veil of ignorance would be motivated mainly by a wish to ensure her own possession of a range of primary goods, rather than by support for the community in which she lives (531). Harsanyi (1975) criticised Rawls' contractarian selection of maximin as the second principle of RA, citing several counter-examples in which use of the maximin principle leads to morally unacceptable outcomes. Harsanyi argued instead for the utilitarian "average" principle, based on prior estimation of the likelihood of good outcomes, averaged over all of those affected by the allocation decision (532). It could be argued though, that Rawls' ideal theory was never intended to be translated directly into practical decision-making, but rather to be used as a general principle and a guide in the rough-and-tumble real world of macro-allocation of resources, where the strict pre-conditions of the original position don't obtain and where there are numerous confounding factors which interfere with pure maximin RA.

The next chapter will discuss the ethical principles which appear to motivate the actions of those who make decisions about the allocation of healthcare resources that affect rural children. Based on the evidence presented in earlier chapters, it will attempt to derive an ethical framework which may better suit the needs and the situation of rural children while at the same time satisfying those of government.

Chapter 8: What Ethical Framework?

The aim of this research was to examine the ethical assumptions which guide the allocation of healthcare resources needed by rural children in Australia. To illustrate the effects of RA performed according to the ethical assumptions which currently inform decision-making, the thesis describes the distribution of those resources in rural areas, and how rural families experience accessing healthcare resources for their child when those resources are distributed in this way. In particular, the candidate aimed to examine the way in which the ethical principles which appear to guide RA decisions lead to the healthcare experiences reported by families of children in rural and remote areas. This chapter will attempt to describe the ethical framework which underpins the allocation of healthcare resources by Australian governments, and suggest a modification to these ethical assumptions which is acceptable in an Australian context and which may lead to better health and developmental outcomes for rural children. To do this, it first briefly reviews the health disadvantage of rural children. It then examines the role of government in providing for the healthcare needs of rural children and discusses the aspects of healthcare that an Australian government might provide for its citizens. Later sections of the chapter explore the components of wellbeing and the applicability of the ethical principles described in the last chapter to decision-making about healthcare RA to rural children. In particular, the meaning of equality in this situation is explored, and the reasons why an Australian government might give extra consideration to the interests of children are examined. A vector model of decision-making by a group is used to explain why a group of individuals who have a moral reason to act in a certain way fail to do so.

8.1 The health disadvantage of rural children

Section 1.8 shows that overall child mortality and especially mortality from causes such as trauma, poisoning and respiratory illness increases with the remoteness of the family's dwelling from major centres of population. It also shows that morbidity from these groups of illnesses increases with remoteness. Data from the Australian Early Development Census show that in 2015, the proportion of children who were developmentally vulnerable on one or more domains increased progressively with remoteness from centres of population and that children in Very Remote areas (see Appendix 1) were twice as likely to be developmentally vulnerable on one or more domain as urban children, and were three times as likely to be vulnerable on two or more domains (533). The Early Development Census examines child development in five domains linked to health and social outcomes (416). Children who are vulnerable in two or more of these domains are more likely to have lower educational achievement, more mental health problems and chronic illness, and as

adults are more likely to be unemployed, homeless and involved with the criminal justice system (401).

A Murdoch Children's Research Institute (MCRI) study performed in 2017 on behalf of the Royal Far West organisation found that children living in rural and remote areas of Australia were more likely to experience poverty than urban children; they were more likely to live in an unemployed family or a single parent household or have a mother with a low level of educational attainment. Children in rural and remote areas were more likely than urban children to be socially isolated, to have experienced family or domestic violence, and they were more likely than urban children to be from an Indigenous family. Each of these factors is independently associated with some degree of developmental vulnerability and hence with the need for early childhood education and care services (416).

The kinds of health services that rural children need include primary care services such as GPs and nurse-led clinics, Aboriginal health centres and maternal and child health clinics, as well as referral services such as paediatricians, early childhood intervention (ECI) services, mental health services, public dental services, paediatric surgical services, ophthalmologists and dermatologists. In addition to these, children with complex care needs require allied health services such as physiotherapists, rehabilitation practitioners and speech pathologists with expertise in the care of children. Too often, as described by officials and health advisers in sections 6.4 and 6.7, these roles are assigned to physiotherapists, rehabilitation and palliative care practitioners (534), and speech pathologists who are expert in the care of adults but have little or no experience in treating children, whose health conditions and care needs differ greatly.

The MCRI study pointed out that ECI services and allied health services needed by rural children were often located in larger regional towns, so that children living more remotely have to travel long distances to attend. Waiting lists are long and trained personnel are few, leaving children needing these services with unmet needs. Paediatrician services and mental health services tend to be located in larger towns and to operate only sporadically (see section 1.12), because training personnel sufficiently to provide these services and persuading them, once trained, to live and work in relatively remote areas has proved difficult, given the well-recognised problems with peer support, ongoing education and spouse/partner employment in country towns (416).

The authors of the MCRI study also reported that access to ECI services which are so important for the progress of children with developmental delay of any cause, or of children with a disability, is particularly difficult for such children who live in rural and remote Australia because of the distances

which families may need to travel and the relative scarcity of such services, leading to long waiting times or complete inability to access the service (401). Mental health and paediatrician services, needed by many of these disadvantaged children, are especially difficult to access (416), at least partly because of the difficulty in attracting appropriately trained personnel to rural and remote areas and the consequently heavy workloads imposed on those who *are* located in rural areas. The location of these services in large regional towns and cities means long travel times and distances for families who live more remotely (401).

The NSWCPHS 2011–14, the results of which are described in Chapter 5, showed that rural parents experienced significantly more difficulty in accessing healthcare for their child and that difficulties increased with increasing remoteness from major cities. Shortages of health services in general, and of GPs in particular, in rural areas, especially the more remote areas, caused difficulty with access to healthcare, notably increasing time on a waiting list for a child to see a GP. This difficulty in access to GPs may be due in part to the apparent trend of rural GPs to work part-time (see section 1.12). The paucity of GPs in rural areas and the prolonged waiting times to see them may explain the fact that rural people were considerably more likely than urban people to attend an ED because no GP was available when needed (380).

Chapter 5 pointed out the problems posed for families of small children by the need to travel long distances to healthcare services and very patchy public transport in rural Australia. The difficulties experienced by rural families (and especially by young single mothers) are exacerbated by the need of the parent to take time off work and for the child to lose school time, especially when regular appointments are needed. Regular long-distance travel also compromises the ability of families to provide satisfactory parenting for the siblings of the sick child. Difficulty in obtaining transport because the family has no private vehicle available and finds public transport too expensive can lead to the service being completely forgone, as described in sections 5.3 and 5.5. This problem of incoordination of healthcare services with transport and its effect on healthcare access was pointed out by an adviser to health departments:

> … *there's the structural things, it gets too hard to negotiate the system so they just don't, you know?* Adviser 1

Parents interviewed for the *Stories of the Invisible Children* report (Royal Far West and Charles Sturt University, 2019) also reported difficulties with transport:

> Where we lived previously [child] would have to go 360km one way to see the paediatric specialist, and then we'd have to go another way, 100km … to see the orthodontist and then

> you'd have to go 200km one way to go to the paediatrician … so we were looking at a 700km round trip once or twice a week, which was physically impossible, so that was one of the big issues for us... (401)

Chapter 5 also described the difficulty in gaining access to specialists for children and problems with quality of care and communication in EDs reported by parents in rural areas. Studies performed in 2007–09 in towns in Central West NSW found that parents, especially those of socioeconomically disadvantaged families, were not well-informed about services that were available for their children (some of whom had complex healthcare needs), nor were they aware of how to access these services nor how to lobby for improved local provision of these services. They also reported that those same families tended to rely on services that were provided locally, rather than travel to the city to access services that may have been more suitable for their needs and those of their children. These families relied heavily on their GPs for coordination of services, even when their GPs were not continuously available (535, 536) (see sections 1.12 and 5.1), and their ability to gain help from the different parts of the health system suffered in consequence: "They've been told in Sydney their child is autistic but they haven't been told where the help might be or what it is" (rural health worker, interviewed by Allan et al., (2009)) (535).

Allan and co-workers described the disadvantage to rural children caused by lack of coordination between state government departments, notably in ECI services for children of different ages, and between housing, transport, education and health departments in dealing with the needs of disadvantaged rural families where these affect non-healthcare determinants of the children's health (535). This lack of coordination was corroborated by officials and advisors interviewed in the present study (see sections 6.2 and 6.6) and was perceived as a major problem by parents interviewed in the *Stories of the Invisible Children* report in 2019:

> I mean this coordination thing is a major problem as well, because you think about it – the amount of money to travel to get a paediatrician – now that paediatrician never talks to the OT [occupational therapist]. You can never get appointments on the same day, ever – or you can't get to see the hearing specialist on the same day either or the ENT [ear, nose and throat specialist] ... And they don't talk to each other ... There's just no integrated approach for kids who have multidisciplinary issues. (401)

8.2 The role of government in providing for the healthcare needs of rural children

Although healthcare contributes to maintaining the health of individuals and of a population, it is not the major contributor (see sections 1.6 and 1.7). While government action cannot ameliorate many of the non-healthcare determinants of the health of a rural child (such as genetic and congenital abnormalities), government-produced laws, regulations and services can reduce the risk of exposure to others such as environmental hazards (e.g. road or farm trauma, poisoning and infections). In the presence of other social risk factors for ill health of a child (such as poverty, social isolation, domestic violence or living in an unemployed family), extra care must be taken to monitor the child's progress and to intervene when necessary to help the child and family gain access to all of the services needed if the child is to make her/his greatest possible progress in health and in educational and social development.

In these circumstances, a whole-of-government approach is needed to minimise the barriers to access to all of the services required. Children with complex healthcare needs such as children with cerebral palsy, traumatic brain injury or survivors of extremely premature birth, too, require coordination of services such as education, transport and social services, as well as healthcare specialties such as paediatrics, paediatric physiotherapy, occupational therapy and speech pathology. When the services themselves are lacking or unsuited to the needs of the child, or access to them is difficult or the services are uncoordinated, the child's health, developmental progress and educational and social attainment are likely to be impaired.

Although Australia has a public health system, its history of reliance on privately provided services and the encouragement by governments, both state and federal, of private provision of some of those services (537) has meant that families in many rural areas whose children have complex care needs are unable to access some services (such as speech pathology, physiotherapy and occupational therapy) in the public system but must instead rely on private providers who charge a fee. Reliance on multiple private services can soon become unaffordable, especially for parents in low-paid jobs or who are dependent on government pensions or subsidies:

> … Just like my husband would say that's 500 bucks. I really don't have $500 for a session of OT … yet that's what it is ... Before you know it, the $500, you multiply that by at least four or five. So ... I'd love to tap into OT … but I just can't ... I feel like the gap sometimes of where – what the kid should be getting and what they are getting just grows. Rural parent interview, *Stories of the Invisible Children* (2019) (401)

8.3 What aspects of healthcare might an Australian government (state or federal) provide for its citizens?

The three main aspects of healthcare are: provision of services and facilities; ensuring access to those services and facilities; and coordination of government services including health, transport, education and social services to ensure the best possible health outcome for all members of the population. Later sections of this chapter discuss the moral considerations that might influence the decisions of a government about whether to provide these services and about their distribution, both geographically and among different subgroups of the population.

Provision of services

These may include primary care services (GP or Aboriginal health service or nurse-led clinics) which also perform some preventive care and health education as well as health monitoring services. These aim to help families who are not well informed about their health to understand their health needs and to gain access to the means of satisfying those needs. A government might reasonably be expected to ensure that even when a community cannot attract a GP to live and practice in the area, a primary care service of some type exists which can perform some GP functions and can help families gain access to the coordination functions described below. It could be claimed that a responsible government should not merely wash its hands of the problem on the grounds that primary care services are supplied by private practitioners and are not under its control, as one interviewed official suggested:

> *… what may also impact that is their access to the GPs for example, which is nothing to do with our state budget …* . Official 3

In view of the high (and rising) proportion of children in rural and remote areas of Australia who are vulnerable in one or more developmental domains (416), a government might provide an ECI service that is capable of identifying all such children and providing appropriate intervention services early enough and consistently enough to guide these children to health, educational and social outcomes that are the best that can be achieved.

As well as primary medical care services, a government might provide a primary public dental service, a primary mental health service and referral services, of medical specialists such as paediatricians and ophthalmologists and of allied health services such as physiotherapy, speech pathology, occupational therapy and palliative care. To cater adequately for the needs of children, these services would have expertise in the care of children with complex conditions (416).

Access to services

The domains of access, described by Penchansky and Thomas (1981) (93), are availability, accessibility, accommodation, affordability and acceptability (see section 1.9). It is within the power of a government (particularly, in Australia, of a state government), to ensure access of all citizens, in each of these domains, with respect to all of the services just described. As noted in section 6.4, there are invariably constraints on the amount of money that can be spent on a service, on the personnel that are available to staff it, and on the degree of perceived risk that a state government is prepared to accept on behalf of its outlying instrumentalities. Given a limitless supply of funds and of appropriately trained personnel and a sufficiently malleable system of government regulation, it would be possible to place all of the services described in section 1.12 conveniently close to all communities in the jurisdiction. It would also be possible to ensure that each of them is affordable even by the least well off, is capable of supplying the healthcare needs of all who require its services, including children with complex health conditions, is culturally appropriate for all its clients, and is accessible by government-provided transport when private transport is unavailable. This might be the ideal.

In practice however, total funds available for healthcare are limited, appropriately trained staff are hard to find and to retain, especially in rural areas (416, 538, 539), public transport is very limited outside the cities, even in Inner Regional areas (538) (see section 5.3), and political and inter-departmental agenda issues tend to interfere with the rational and fair allocation of resources (see section 6.4). Health facilities which provide services for rural communities are not always culturally adapted to the needs and expectations of their Indigenous clients. As one adviser pointed out during the interview:

> *There's also the whole sort of the cultural acceptability of a place and it's not only for Aboriginal people … culturally, linguistically diverse people it's also you know, for rural people going to an environment which is pretty foreign there's that sort of, they don't like the city, they don't like the traffic lights, they don't like the pace of things, so there's those sorts of things that get in the way that they think, nah it's too hard I don't want to do this*… Adviser 1

Furthermore, as Allan et al. (2009) found, parents in rural areas, especially those in poorer socioeconomic groups, often lack information about their child's illness and about the help which the child needs, how to access it, what alternatives there are and what outcomes to expect and to aim for (535, 538). Despite all of these inadequacies in the various domains of access to health services which exist currently, they are all capable of improvement, if not of complete rectification,

given sufficient motivation on the part of decision-makers and of those whose work they supervise. What this motivation might consist of is described in later parts of this chapter.

Coordination of services

The problems of lack of coordination between instrumentalities of the same government department, between departments of the same level of government, between departments of state and federal governments, between state government departments and local government, and between government and private healthcare providers are described in sections 6.2 and 6.6 and are widely recognised:

> *My passion is to get all the specialists under one roof – all the therapists together. That's where the most effective gains are made because you have joint meetings and you're constantly talking about this student or child and working out what's best and you're all working together under one roof*. Health professional interview, *Stories of the Invisible Children* (2019) (401)

> *It took us nearly two years to get to the point of going to Royal Far West. We saw Community Health, we saw education providers, both in early childhood and school age. We saw doctors, we saw speech therapists, we saw paediatricians – we were going this full circle for about two years before we finally got in the door at Royal Far West and we saw everybody again, all under one roof, which was great.* Parent interview, Cumming (2019) (538)

These quotes point out the benefits of a care coordination service, in this case offered by Royal Far West, a charitable organisation operating in rural NSW. The same coordination role could be considered to be an essential function of government, especially of Australian state governments which have transport, education and social service functions within their purview. Care of the vulnerable family is needed to care effectively for its vulnerable child, as pointed out by two of the interviewed officials:

> *In these communities, if you don't support the family, you don't help the child*. Official 4

Provision of this kind of support may involve coordination of the activities of health, education and social services departments and those of local government, as well as local volunteer services (e.g. for ad hoc transport needs). This kind of coordination requires a coordinator with access to a database of available services and of effective contacts within each service. Coordination of care has not been seen hitherto as an obligation of government, but it is clear from the evidence gathered by

investigators from academic institutions (416, 535, 536, 538), sometimes on behalf of non-government organisations (416), that in order to achieve a desired health outcome in a disadvantaged population (in this case, rural children), it is necessary to ensure that the functions of caring agencies dovetail to prevent disadvantaged children from falling through the cracks. Given the clear evidence of the health disadvantage of rural children, it is not sufficient to assume that the child's parents can or will perform this advocacy and coordination function, as one official suggested:

> *This is the parents' responsibility, at least in part.* Official 6

Nor can health departments assume, as one official claimed, that the interests of a child with healthcare needs will take precedence, over the interests of the parents, the siblings or the family as a whole in the family's decision-making:

> *I think the evidence...suggests that parents will actually put their children's needs in advance of their own needs for health…* Official 1

It is not beyond imagining that a state government might establish and continue to support a coordination service, equipped with the databases and contacts as described above, and with experience of available referral services, and with personnel who can travel to regional and remote parts of the state to oversee the integration of care for individual children. This service might be available to primary carers, whether GPs, nurse-led clinics, Aboriginal health services or mental health services to arrange ongoing care that is beyond the immediate capability of the primary carer. This overarching service could be a government function which makes the coordination services now provided by organisations such as Royal Far West in NSW available to all. To make changes in the structure, function and location of services in order to ameliorate the known health disadvantage of rural children, health department decision-makers require a reason to make those changes.

8.4 What should a government health department aim to provide for persons in its jurisdiction?

The answer to this question varies from country to country according to the conception of the role of government which prevails in that country. In the US, for example, where only 49% of total healthcare spending is publicly financed (540), the role of government (federal, state and local health departments) concerns provision of safety net healthcare services like Medicare and Medicaid, public health, health monitoring, health research and the regulation and supervision of private services. State and federal health departments in the US have extensive and active social

service branches to care for the needs of groups of disadvantaged citizens such as the disabled and the elderly, but although the mission of the US Department of Health and Human Services is "to enhance and protect the health and well-being of all Americans" (541), the focus of government, as well as that of private providers, in improving service coordination appears to be on increasing efficiency of healthcare service provision rather than on improving the overall wellbeing of all citizens (542). The World Economic Forum, which, though based in Geneva, reflects the libertarian position (see section 7.2) which is associated with government in the US, states in its agenda that the three responsibilities that every government has towards its citizens are: to protect its citizens from violence; to provide the goods such as roads and bridges that individuals can't provide for themselves; and to foster talent. There is no mention here of improvement of the quality of their lives or of maximising their life opportunities (543).

In Australia, which has universal publicly funded health insurance, supplemented by private insurance and private healthcare providers, state and federal health departments advertise their goal of improving the wellbeing (not just the health) of their citizens, and state health departments advertise, in general terms, the means by which they propose to achieve that goal. The Federal Department of Health's stated aim is to "work towards achieving better health and wellbeing for all Australians, now and for future generations" (544). The ACT Government plans to implement a Health Check of all Year 7 high school students in order to "improve the overall health and wellbeing of our young people" (545). The Victorian State Government, in its Public Health and Wellbeing Plan 2015–19, outlines the social and environmental determinants of health and of wellbeing, and expresses the intention of the State Government to ameliorate these, without going into detail about exactly what action is proposed. These examples show that Australian governments are at least aware that the wellbeing of individuals in the population can be affected and improved by government action (546).

8.5 What are the components of wellbeing?

Health and happiness are generally agreed to be important constituents of wellbeing, as are freedoms to be as one wishes, and to fulfil one's life goals (547). Amartya Sen (1993) described wellbeing in terms of capabilities to achieve functionings that are valuable to the individual, where functionings are

> … parts of the state of a person – in particular, the various things that he or she manages to do or be in leading a life. The *capability* of a person reflects the alternative combinations of functionings the person can achieve, and from which he or she can choose one collection. (195)

The wellbeing of children has additional components. As well as the objective aspects such as health, access to shelter, water, adequate food and education, freedom from hunger, poverty and danger and the subjective mental-state aspects such as happiness, freedom from pain and perceived freedom to fulfil her wishes, which reflect the child's *current* state, there is the consideration, which may not be perceived by the child, of the presence or absence of the circumstances needed for *becoming;* that is, for developing towards adulthood and for fulfilling her or his potential (548).

The determinants of a child's wellbeing, then, are the determinants of its various components. Section 1.5 describes the various determinants of health, including its social determinants, and section 1.6 describes the contribution of healthcare to health. Apart from their role in influencing the state of the child's physical and mental health, factors such as socioeconomic status, adequacy of housing and nutrition, social isolation and stresses within the family have an additional effect on the child's wellbeing, both on its current and its becoming components (548). A government which was truly intent on maximising the wellbeing of all members of its constituency would do all in its power to ensure that these determinants of the child's current wellbeing and of the becoming aspect of her wellbeing were secured, and secured in a way which optimises their benefit for the child.

Of particular relevance to the central argument of this thesis is the effect on the wellbeing of the rural child, and on her family, of the way in which healthcare resources are distributed. As section 1.12 shows, all of the healthcare resources that are available to urban children are, in theory, available to the child who lives in a rural or remote area. If a specialist paediatric or allied health service is not available in a nearby town, it will be available in a paediatric hospital in the city, though this may be several hundred kilometres (and many hours of travel) distant. Section 1.12 also shows, however, that for many children and their families, gaining access to these resources does frequently require long-distance travel, and as sections 5.2 and 8.1 show, involves extensive loss of school time and home rest and relaxation for the child, loss of work time and work income for at least one parent, and disruption of normal family functioning and relationships. The stress of childhood illness may be to some extent unavoidable, but the extra strains imposed by distance and by the relatively poor quality of service experienced by some families in rural areas and the complete lack of suitable, accessible services experienced by others (sections 5.2 and 8.1) imposes avoidable strains which can and do have significantly deleterious effects on the child's development and on her health in adulthood (548). Accumulation of childhood stresses such as these, apart from impairing the child's current wellbeing, also leads to increased likelihood of chronic disease such as coronary artery disease, chronic lung disease, cancer, alcoholism, depression and drug abuse in adult

life (549). Clearly, not every rural child will suffer these adverse outcomes, but rural health disadvantage in both adults and children is clearly demonstrable (425), and the role of these mechanisms in the genesis of disadvantage in health and wellbeing have also been shown (549).

Schooling loss alone has a significant effect on wellbeing and development. *Missing School 2015*, a report on the 1.6% of Australian children who experience significant schooling loss due to illness or injury, described its effects on academic attainment, anxiety and behavioural problems, relationships with peers, engagement and motivation when at school, self-esteem and social isolation from peers and from the school community, with consequent effects on the child's emotional wellbeing (550). While this report concerns the severe end of the spectrum of schooling loss, lesser degrees of time out of school – such as those experienced by children in rural or remote areas who have a recurrent need to access healthcare in a distant town – can have similar ill effects, though of lesser severity. When the need for schooling loss is ongoing (e.g. for a child with chronic or complex illness), the effect of recurrent loss of school time is cumulative (551).

In view of the known disadvantage of rural children in the determinants of health and of wellbeing, and given the declared interest of federal and state health departments in Australia in ameliorating both, two questions arise: do rural children have a case for special consideration for the allocation and detailed organisation and integration of healthcare resources which might improve their health and wellbeing? And, why have the declarations of good intent not been translated into outcomes which reflect the Departments' declared aim? These questions are addressed in the next section and in later parts of this chapter.

8.6 Do rural children have a case for special consideration in the allocation of healthcare resources?

Rural children have more difficulty gaining access to healthcare resources than rural adults

Rural children share all of the disadvantages in access to healthcare that are experienced by those rural adults who are fully dependent on others for their access (105, 535), with the additional difficulties that for several types of service, such as physiotherapy, speech pathology, rehabilitation and palliative care, the service providers who *are* available in the area are trained in the care of adults, with little or no training in the needs or care of children (105, 123, 416, 552). This problem is particularly acute for younger adolescents in rural areas with mental healthcare needs (416). Those

specialist services which are available in regional areas, because they are so few, must cater for large numbers of children, so access to them is difficult and waiting times are long (553).

Specialist services that children often need (such as paediatric orthopaedic, paediatric oncology, paediatric surgery) are more likely to be located only in a city than are the equivalent services for adults. This adds to the difficulty of healthcare access for the ill rural child and her family, especially those living at great distances from the city (416, 534). A Canadian study in 2001 showed that in families with children with chronic illnesses, the greater the distance the child needs to travel to access healthcare resources, the greater is the strain on the family unit, and the greater the impairment of the relationships (child–parent, child–sibling and parent–parent) within the family which the child needs for normal social development and functioning (554). All of these findings indicate a significantly greater disadvantage in access to healthcare for rural children than for rural adults.

Limitations on a child's ability to access healthcare resources for her/himself

Apart from obvious, external issues such as dependence on adults for transport and financial resources, the child's access to healthcare resources is limited by several development-related considerations. Experience of health resources and how to contact them, and how to make use of them for one's health needs, only accumulates in late childhood and early adolescence. Children who have had little exposure to healthcare structures and clinicians under the tutelage of their parents will eventually learn how to make independent use of these resources (by direct or proxy – e.g. via media – experience), but may gain that skill later than children who have extensive early exposure (109, 110).

The executive skills, such as attentional capacity, planning and problem-solving skills and working memory, needed for an individual to interact independently with healthcare organisations develop at different times in different children, but in most children are not well-developed until early adolescence (111, 112). This means that children in middle or late childhood should not be expected to be able to assess their own healthcare needs or to plan and execute a consultation with a healthcare organisation.

The developing ability of a child to interact with and use community structures such as healthcare resources depends on accumulation of social skills, or competence. "Competence" as a concept is specific to the culture in which the child is raised, so that skills which may be relevant to the wider society may be less relevant and may only develop later if at all in subgroups within that society. For example, studies of Latino and African-American children and adolescents in the 1960s and 70s

assumed a wider-society norm, which was that of a middle-class white society with its particular values and expectations of specific skills which a child should develop (555). As Ogbu (1981) pointed out in, although educational measures intended to remedy "deficiencies" in the development of competency in minority group children were not successful in engendering the competencies expected in the wider white middle-class society, some of these children did well in school, and in any case, the skills learned from their parents and others around them were highly appropriate to the milieu in which they were raised (110). The same could be expected to be true of minority groups in pluralistic societies such as that of Australia. Davies and McKelvey, for example, found that while immigrant adolescents in Western Australia had fewer competencies (defined by white, middle-class norms) than their non-immigrant peers, they also had fewer behavioural and emotional difficulties than non-immigrants (556). Language and inexperience of Australian community resources, however, are likely to limit the ability of immigrant children and adolescents to access healthcare resources independently of their parents.

Given the rural child's known health disadvantage compared with urban children (see sections 1.8 and 8.1), difficulties in access to healthcare compared with urban children (see sections 5.2–5.5 and 8.1) and compared with rural adults (as shown in the previous section), and the rural child's dependence on others for access to healthcare, what moral principles might lead a government to make RA decisions that favour the health and wellbeing of rural children over other groups in Australian society?

Moral reasons for giving priority in healthcare resource allocation to rural children

The first reason to discuss, because it has been extensively proposed to support child priority in healthcare, is the utilitarian view that the health of children should be ensured before that of other age groups. This is because the children of today will become the foundation and the drivers of tomorrow's society (557-560).

Utilitarian reasons

Studies in Australia and in high and low-income countries elsewhere have demonstrated, using economic modelling, the putative economic benefit to countries and the high benefit–cost ratio of preventive and early intervention measures in healthcare. The benefit–cost ratio (in dollar terms) of instituting best-practice early intervention mental healthcare for Australian children and young people, for example, was calculated as 5.6:1 (557).

The problems with these studies are first, that they are based on models, which may not take account of all relevant contributors to outcome. Second, if they study a single disease/treatment issue, given the time taken to collect information on sufficient numbers of precisely defined conditions and treatments, their data are generally out of date by the time they are analysed and published. Third, models inclusive enough to study sufficiently large numbers of individuals with a heterogeneous range of cultural, socioeconomic and health backgrounds give results that are too broadly defined to be a precise guide to action.

Even if the results of these reports were believable and accurate, the presumption which underlies them is that a government should aim to achieve the best economic outcome overall. In order to do that, a government should invest only in those individuals who are most likely respond to the treatment modalities offered, who are least expensive to treat and who are most likely to become taxpayers and not require prolonged healthcare or social security benefits. The criterion by which the type and degree of illness appropriate for government support should be judged, then, is the point at which the benefit–cost ratio starts to fall when illnesses of progressively greater severity and chronicity are added to the list of those supported by government. Since healthcare in general is more expensive to deliver in areas remote from cities than in large population centres, a utilitarian justification for healthcare RA seems unlikely to favour better healthcare for rural children, especially those with chronic or complex conditions.

The rights of the rural child

Section 7.11 examined the nature and justification for the concept of rights, and discussed the question of the rights of the child. That section also pointed out that one of the preconditions needed to be a possessor of rights is to be a moral agent (423, 504). Griffin (2002) claimed that although infants do not possess rights, children acquire rights as they acquire agency (518). The child, even in infancy, may also be said to possess some basic rights such as the right to life, to freedom from harm and to nutrition in virtue of her potential to become a moral agent. The child's arguable possession of these basic rights in infancy, however, cannot support the assignment of priority in healthcare RA to rural children, because the healthcare resources which rural children need are certainly available to them, though in the case of many children, only at an impracticably great distance from the child's residence.

Even the welfare-based child rights proposed by Brennan and Noggle, consisting of basic rights to nutrition, rights not to be killed or harmed, plus rights to be educated and "to develop the capacities to satisfy her own needs and exercise her own rights" (521) do not appear to address the issue of the disadvantages in health outcome and in healthcare access described in sections 1.8 and 8.1.

Since the disadvantage described there is disadvantage *relative* to the situation of urban children who are citizens of the same society, the moral principle which might correct this demonstrable unfairness must address relative benefits accorded to different groups in the society, rather than the absolute benefits (or rights) to which a group is entitled. What the rural child perceives, however, is *his* state of health and *his* level of wellbeing, rather than his state compared with that of (unseen) urban children, so a rights-based case can be made for provision of at least a safety net minimum of nutrition, housing, education, clothing and family relationships for all children. At what level this safety net minimum should be set in a high-income society such as Australia though, is unclear, and as Norman Daniels pointed out, a rights-based account of RA cannot define it (274).

Fairness

John Rawls' ideal theory of justice postulates that the resource allocator should behave in her decision-making as if she were behind a veil of ignorance (see section 7.12) in which she is aware of the nature of the society and of its resources, but unaware of her own age (i.e. whether she is a child of any age or an adult), gender, race, socio-economic status, geographic location or conception of the good (45). Rawls' theory, based on the self-interest of the individual and on the social contract, was that a rational agent in that position would allocate resources according to two principles, in the following order of priority: first, that each person should have an equal right to as extensive a system of basic liberties as is compatible with a similar amount of freedom for others, and second, that social and economic goods are distributed such that any inequalities are to the greatest benefit of the least advantaged (45).

If Rawls' theory is adapted to the situation of healthcare RA which affects rural children, several points must be specified. First, the allocator should act as if unaware of whether he was a child or an adult, of his geographic location (urban, rural or remote) and of his own degree of disadvantage (socio-economic, underlying health status, family dysfunction, transport access etc). Second, the goods to be distributed are healthcare resources and their capabilities and location, and their coordination with each other and with other government functions. Third, when inequalities are of benefit to the least advantaged, that disadvantage may consist of any or all of those just mentioned, but may also include the child's degree of dependence (for decision-making and for healthcare access), her/his underlying health condition (e.g. genetic, chromosomal or other congenital conditions, acquired conditions such as cancers or traumatic brain injury) and family interests which conflict with the child's interests in obtaining access to healthcare (see section 1.13). Clearly, some of these domains of disadvantage are shared by groups of children, while particular combinations of domains of disadvantage and the degree to which each is expressed will be peculiar to individual

children. This means that fairness in RA guided by Rawls' theory would require that the allocation be tailored to individual children.

As in the account of rights-based RA, described above, what is allocated are resources and their organisation, so this is justice as seen from the point of view of the allocator. Unlike rights-based allocation, the end-point of Rawlsian allocation is that the most disadvantaged (in terms of the domains of disadvantage just described) achieve a better overall health and wellbeing outcome than they would experience with any other possible pattern of RA. As section 7.11 describes, however, this allocation principle does not necessarily improve the situation (health or wellbeing outcome) of the most disadvantaged *relative* to the more advantaged, though it does deliver their best *absolute* outcome that can be achieved by any pattern of healthcare RA. However, Rawlsian allocation assumes that the allocator is prepared to distribute resources away from the more advantaged, and this was something that the officials interviewed were reluctant to consider. As one of the advisers put it:

> *I think that one of the problems is we don't have the opportunity to discuss those things more as a community*. Adviser 2

This reluctance, and the known sensitivity of political decision-makers in Australia to the media criticism which follows withdrawal or reduction of a service which has been provided hitherto, makes it unlikely that they will agree to a pattern of reallocation of resources that exposes them to electoral risk. Two of the officials described this political disincentive:

> *To* [increase the resources available to rural health authorities] *you've got to not just have the technical efficiency bit going on, but you've got to have the reallocation going on. And I think that's where it gets very difficult*. Official 1

> *Those things are quite challenging when there's already an established service and expectation*. Official 8

Communitarianism, compassion and solidarity

The basis for communitarian claims (see sections 7.8 and 7.9) concerning healthcare RA is that it is only because we are members of a community that we are required to have any ethical reasons for actions (470), and it is only our membership of a community that defines us as moral agents. Gavin Mooney suggested that government should adopt a communitarian viewpoint for healthcare RA, rather than one based on the interests of the individual, such as a contractarian or a fairness-based viewpoint, for the utilitarian reason that Program Budgeting and Marginal Analysis (PBMA – see

section 2.4) is more likely to be implemented and can be implemented more effectively if communitarian assumptions rather than individual interest assumptions are made (281).

The communitarian position and the related viewpoints of compassion and solidarity (see sections 7.9 and 7.10) emphasise the responsibility of individuals for the wellbeing of others in the community, and encompass the notion that we are all members of multiple communities (family, village, workplace, state, nation, mankind). This mutual responsibility based on shared humanity supports action to optimise the welfare of others, and in particular that of the disadvantaged (281, 486). The communitarian tradition is long, but its role in RA has been expounded in modern times by writers such as Daniel Callahan, Martha Nussbaum and Gavin Mooney (281, 476, 561), all of whom wrote in anglophone countries, where the prevailing dominant philosophical tradition is that of consideration of the freedom, rights and interests of the individual. If government decision-makers in Australia were to adopt a communitarian or solidarity approach to decision-making, it would require their adoption of a framework of consideration of the obligations of the individual towards others that is quite contrary to the anglophone tradition of individual interests as a basis for consideration of obligation towards others. Furthermore, that change in the basis of obligation would have to be uniformly adopted across all those who have responsibility for decision-making about healthcare RA, in order for the reasons for decisions to be understood and agreed. It seems unlikely that such a change in the foundations of a shared ethical framework and a departure from the implicitly assumed heritage of Hobbes, Hume and Locke could occur among Australian decision-makers.

Equity

Despite the evident disparity in health outcomes between rural and urban children in Australia (described in section 1.8) and despite clear evidence that rural families are significantly more likely to experience difficulties of various kinds in obtaining healthcare for their child (as described in Chapter 5), Australian officials, both elected and unelected, stated in interviews that the achievement of equity in healthcare RA is the moral consideration that characterises a good allocation decision:

> *This* [decision] *was good because it increased equity …* Official 7

Moreover, officials emphasised that vertical equity (treating unequals unequally – see section 7.5) was an essential part of making healthcare RA decisions which affect individuals and communities of different degrees of socio-economic advantage and disadvantage. It is not clear however, what good is being targeted by Australian government health departments when they claim to distribute goods

in favour of the more disadvantaged. In some cases, it appears to be an increased allocation of healthcare resources to the disadvantaged:

> *A government will mostly try to weight its allocations towards the disadvantaged*. Official 6

In other cases, it appears that resources are allocated in such a way as to improve the health, or possibly the wellbeing, of the most disadvantaged (including children, when they are seen to be disadvantaged). It is not clear, however, whether this improvement is intended to be an absolute one, or an improvement relative to the health or wellbeing of more advantaged citizens.

> *Most programs, even if they don't explicitly target the most vulnerable, will have provisions alongside them which are intended to improve the situation of the most vulnerable*. Official 5

It is also unclear what features of a person lead health department decision-makers to consider them as vulnerable or in need of extra allocation. Do they, for example, take into account the degree of dependence of children on adults for healthcare access, or the fact that in this dependent state, their interests must compete with those of siblings, of parents and of the family unit as a whole? The comments of some officials suggested that they recognise that these are significant impediments to gaining healthcare access:

> *The child's difficulty in accessing healthcare is an important consideration* … Official 6

> *Access* [to healthcare] *problems for children are even more acute than for adults*. Official 4

Others appeared to feel that children were well looked after by their parents and the task of overcoming the access disadvantage of children (including, by extension, that of rural children) belonged to their parents. One official stated this position explicitly:

> *I think for young children we can assume their parents are reasonable proxies [for ???].* Official 1

As pointed out in sections 8.1 and 8.2, this partial abdication by government of responsibility for overcoming the disadvantage in healthcare access experienced by rural children (described in chapter 6) is one of the factors which has led to the situation of children's interests in obtaining healthcare being subordinated to the interests of adults. When the distribution of goods among a group of individuals (e.g. all human beings in NSW) is being considered, several issues must be considered: first, what things are considered goods? Second, is the total of distributed goods fixed, or does it change over time? Third, if the goods are to be distributed equally, what does equality mean in this context? Fourth, who has a claim on receiving a benefit?

8.7 What goods are distributed?

The nature of the specific resources which a health department can distribute is discussed in sections 8.3 and 8.9. The general topic of equality (a descriptive term) and equity (the normative version of the term equality) is discussed in sections 7.5 and 7.6. Among the various forms of equality described by Gavin Mooney (2003) that one might aim to achieve, if motivated by a desire to distribute resources equitably, the variant which appears most applicable to the situation under discussion is equality of opportunity for access to healthcare resources for equal need (section 7.5) (453). As explained in section 7.5, equality of per capita expenditure is equivalence considered from the supply side and takes no account of the cost of supplying services to different groups (e.g. it is more expensive to supply a service to rural than to urban areas) or of groups having different needs. Similarly, equality of per capita resources supplied (section 7.4) takes no account of differences in need or of differences in barriers to access. Equality of resources supplied for equal need (section 7.4) takes no account of access difficulty. Measurements of resource utilisation for equal need (section 7.4) are affected by the availability of the resource and by ease of access to it as well as by the knowledge of families about the resource, so are not a useful index of equitable distribution.

Aiming to distribute resources according to need is unsatisfactory when need is measured in sparsely populated areas, and when need arises sporadically, as the need is likely to be under or over-estimated when prevalence estimates are made only intermittently.

> … [the system] *doesn't cater for needs that appear sporadically*… . Official 4

This problem could be overcome though, by more sophisticated surveillance methods with real-time reporting of incidence of new needs, and more flexible methods of responding to need.

> *… a small town may have no child with cerebral palsy or no child needing palliative care for ten years, but when one does suddenly appear, the health system should have some means built in to cater for that sporadically occurring need*. Official 4

From the State's point of view, then, looking at its obligations to the whole population in its jurisdiction, what is needed is a pattern of healthcare RA which offers equality of opportunity for access to healthcare resources for equal need. From the point of view of an individual rural child, what is needed from the State is that pattern of distribution and organisation of resources (health, education, transport and social service) which optimises that child's wellbeing in all its aspects (as described in section 8.10).

At any given moment, each individual's health is affected by multiple factors, some of which are potentially remediable (e.g. treatable infections or cancers, seizure disorders or asthma), while others (such as genetic disorders or the effects of traumatic injury) are irremediable but their ill effects on wellbeing are potentially reducible or further deterioration is preventable by some combination of healthcare measures. The healthcare needs of the individual are those measures which are needed to remedy any remediable conditions and prevent any preventable deterioration in health, so as to optimise the individual's capability of those functionings which the individual chooses to make her life go well (195) or to optimise her ability to pursue her life plan (274).

8.8 What does equality mean in this context?

In this context, "equality" means equality in opportunity for access to healthcare resources for equal need. Comparing the nature and magnitude of the healthcare needs of individuals is difficult, especially when one is a six-week-old baby with vesico-ureteric reflux, another is a 14-year-old with severe depression, and a third is an 85-year-old with diabetes and heart failure. That difficulty is magnified when one group shares the disadvantages of youth, dependency and remoteness of residence but is otherwise heterogeneous in its health status, while the rest of the population is heterogeneous in the severity and nature of all of those disadvantages. Section 2.4 points out that a need relationship is in the form of A needs B in order to do (or be) C. C in this instance is to be understood as wellbeing (of which health, as described in section 1.4, is a component), a valuable end in itself, though Sen pointed out its instrumental value as permitting capabilities of functionings which are needed for a person's life to go well (195). In emphasising the instrumental value of health, Amartya Sen described it as "a critically significant constituent of human capabilities which we have reason to value" (528).

Is the total of goods to be distributed fixed?

If achievement of vertical equity (see section 7.6) depends on reallocation of a resource such as funding, of which the total is fixed, then either some services which may benefit other groups in the population must be withdrawn, which – as shown in sections 2.4 and 6.3 – is extremely difficult politically, or the new allocation must await an increase in the total of funds available. However, as pointed out in section 8.13, one of the goods to be distributed is the meticulous organisation of government services, which may not involve the reallocation of a scarce financial resource, and so may occur without increase in the overall funds available for distribution.

8.9 Do rural children have a claim to receive an extra benefit?

A motivating principle claimed by health department officials who were interviewed in the present study is preferential allocation to the worse off (vertical equity (211, 453)) in line with Rawls' difference principle (45). Methods of allocation that give priority to particular groups in the community, such as allocation of extra resources to a group based on age per se, have been proposed on utilitarian grounds (557, 558, 562, 563) and on the rather pragmatic grounds of youngest first, prognosis, save the most lives, instrumental value and resources already invested in an individual, which are the bases of the Complete Lives System (564). The Complete Lives System has been criticised on the grounds of unfairness by Norheim (565) and by Kerstein and Bognar (566), among others. Prioritarian allocation (in favour of children) on the grounds of age alone was also rejected in a survey of the opinions of 551 adults from urban and rural Australia (313).

As outlined in sections 1.9 and 8.1, however, rural children can be considered to be a significantly disadvantaged compared with their urban counterparts. Comparison with urban children in respect of their relative disadvantage appears to be the most meaningful comparison, because the two groups of children are more similar in most respects than are rural children and rural adults, for example. The World Bank reported that in 2011, infant mortality in remote and very remote Australia was almost twice that in Australian cities (but was lower than that in 137 of 212 countries surveyed) (466).

8.10 Why might a government decide to allocate services to benefit rural children?

A government's reason for deciding to act in a certain way depends in part on how the decision is made and on who is doing the deciding. The ways in which RA decisions should ideally be made and the ways in which they are made in practice are discussed in sections 2.4–2.7 and chapter 3. In Australia, while departmental officials and advisers make decisions on what advice to offer to health ministers and to cabinet, the final power to decide the programs and other healthcare resources on which state funds will be spent rests with cabinet, either federal or state.

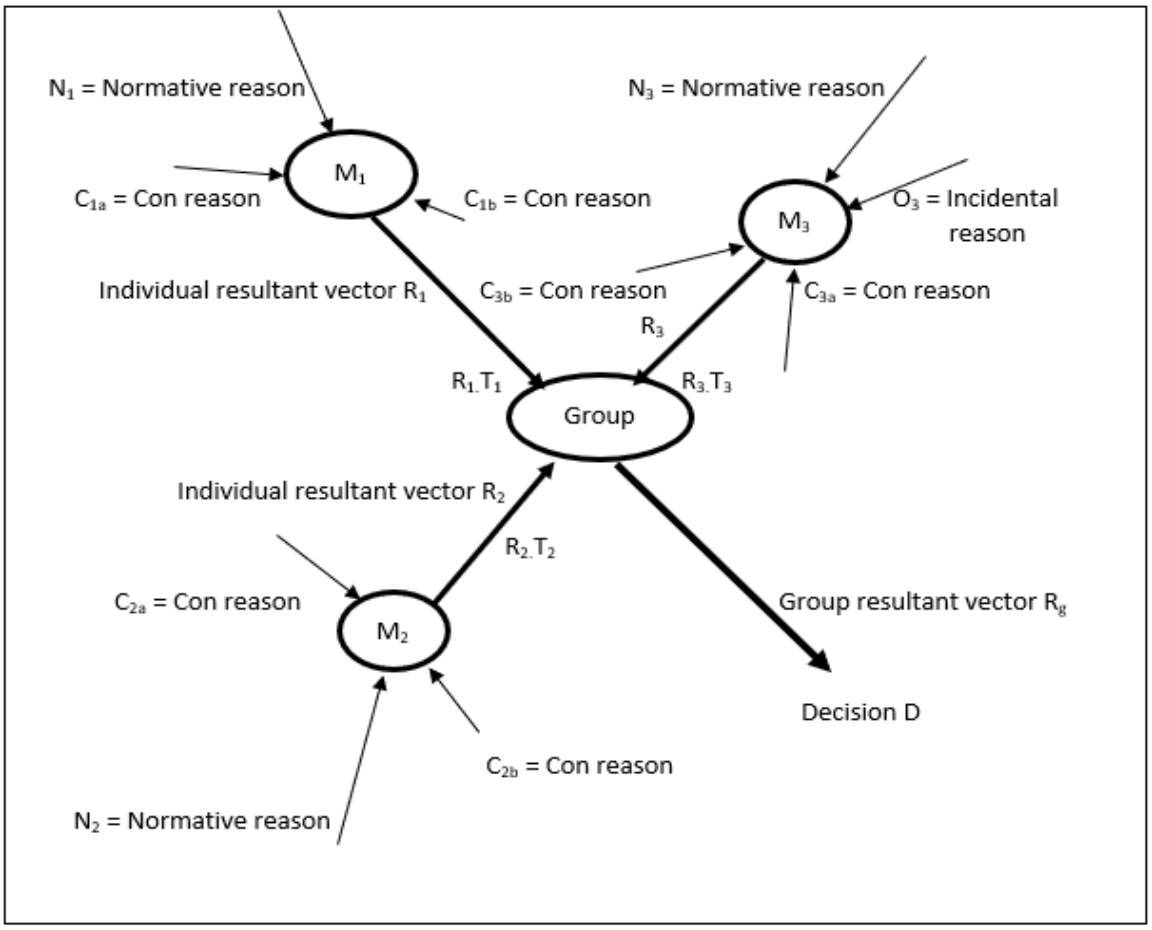
A vector model of RA decision-making by groups such as cabinet, including the ethical motivation of individual members of cabinet, is described in section 8.5 below. The purpose of this model is to illustrate the concept of influences on decision-making by a group, and the way in which those influences have their effect. The model is not intended to be quantitatively precise, nor to have predictive accuracy. Health ministers, federal and state, have some discretion over the allocation of funds within programs, over advice given to cabinet and over the allocation of un-directed funds

between programs in a fixed departmental budget (see section 2.5), but discretion over most RAs resides in cabinet.

8.11 A vector model of group decision-making

A simplified model of decision-making by a group (567, 568) (in this case, members of the state or federal cabinet) illustrates the relationship between the influences on individual members of the group, the power of individuals in the group and the decision that is made (Figure 16). In this model, the group consists of n members ($M_{1...n}$), illustrated as M_1, M_2 and M_3 in Figure 16.

FIGURE 16 A SIMPLIFIED MODEL OF GROUP DECISION-MAKING



In this model, the group is to make a decision D on the allocation of healthcare resources. D consists of several different parts ($D_{1...d}$), of which some are binary (e.g. a new hospital will be built in town X, yes or no) while others are scalar quantities (e.g. an amount of money or a number of staff). These individual parts ($D_{1...d}$) of the overall decision may refer to what, where, how many, how much resource(s) will be allocated. Each individual member of the group (M_1, M_2 …. M_n) offers advice R to the group on decision D_e which is the e^{th} part of the overall decision D. For M_m, the m^{th} member of

the group, R_m, can be regarded as a vector which has magnitude and direction which are the resultant of the individual influences on M_m. The direction of advice R_m represents the nature of the advice ("yes" or "no" for binary decisions and "greater" or "smaller" for scalar decisions such as decisions about amounts of money or number of staff). The magnitude of R_m represents the force with which cabinet member M_m presents that advice to the cabinet group.

The magnitude of R_m is multiplied by a factor T_m which represents the relative influence of member M_m within the group, so that the effect of member M_m on the group decision is the direction of R_m, delivered with force of magnitude R_mT_m. The sum of the individual influence factors $T_{1...n}$ of all members of the group equals 1. The values of $T_{1...n}$ vary according to the nature of the decision to be made, as T_m of the treasurer, for example, may be greater for financial components of the overall decision D than for components concerned with the exact services to be offered by the facility. In general, though, the premier (or prime minister), the treasurer and the relevant minister (e.g. the health minister) will have greater influence on decisions and so larger values of T_m than other members of the cabinet. Individual values of T_m may vary from moment to moment, according to external circumstances such as power relationships within the political party and within the Cabinet, and electoral considerations such as occupation of a marginal seat.

The final decision of the group (R_g) is then the resultant of the individual vectors, of direction and magnitude $R_{1...n}T_{1...n}$, each contributed by a member of the group. In the case of the final group decision, D_g represents that which is decided, and its magnitude R_g represents the resolve with which the final decision is held and its resistance to subsequent external influences. The vote or advice which an individual cabinet member M_m offers to the group can be regarded as the resultant of all of the relevant influences on that member. Each of those influences has its own magnitude (its importance as felt by the member M_m) and its own direction (towards "yes" or "no", in the case of binary decisions, and towards some number or amount in the case of decisions about scalar quantities).

In Figure 16, $M_{1...3}$ are members of the group. N_1 is a normative reason and its accompanying belief, apprehended by M_1, that the group should take action A_g. N_2 and N_3 are normative reasons and accompanying beliefs apprehended by M_2 and M_3. C_{1a} and C_{1b} are "con-reasons" (reasons why not to act according to that normative principle: e.g. expense, lack of available trained personnel in the rural area, etc.) and their associated beliefs (see section 8.14) apprehended by M_1. C_{2a} and C_{2b} and C_{3a} and C_{3b} are con-reasons for M_2 and M_3 respectively. O_3 is an incidental influence on M_3. The direction of each arrow represents the direction in which each of these influences affect the vote of that group member in the final group decision, and the length of each arrow represents the force of

each influence which is apprehended by the member. R_1 is the resultant of the influences (N_1, C_{1a} and C_{1b}) on member M_1. T_1 is a multiplier which represents the influence of member M1 within the group. R_g, the decision outcome of the group, is the resultant of the vectors R_1T_1, R_2T_2 and R_3T_3.

The influence on individual group members that is of interest to the present investigation is the normative reason which each individual might have for offering advice A_m, that the group should perform action A_g. The belief that accompanies that normative reason has a strength which is determined by the importance which the individual attaches to following the normative ethical principle involved (e.g. that all citizens of the state should have equity of access to the healthcare resource being distributed) and which is represented in this model by the magnitude of its vector. Other influence vectors act on the individual group member M_m. Some of these are con-reasons, while other influences O_m on M_m may be non-normative but incidentally act in the direction of giving the same advice, A_m, as the normative reason (e.g. the proposed hospital would be in my electorate).

The normative reason apprehended by a group member may differ in nature, and its accompanying belief may differ in strength from one member of the group to another: thus, one member may have a strong belief that the ethical principle that should be adopted is utilitarian – the best overall outcome summed over the whole population – while another may have a weaker belief in the need to ensure equity in access to healthcare resources. Some members may be unaware of any normative reason for offering advice A_m that the group should take action A_g, and may not be conscious of holding any accompanying normative belief at all (as some interviewed officials claimed – see section 6.5). Other members of the group may hold more than one normative belief with its accompanying reason for offering advice A_m; for example (as noted by other officials – see section 6.5), decision-makers aim to achieve vertical equity (in RA or in access to resources), although in the background, they are also motivated by the need to achieve the best possible value for money in terms of improvement in health outcomes. A member may be influenced by one normative reason and its accompanying belief (e.g. in the need to get the best overall health outcome for the money spent) for one decision, but be more influenced by the need to achieve vertical equity in access for another decision.

8.12 Reasons other than moral reasons for resource allocation decisions

A variety of reasons other than moral ones determine why a government might decide to allocate healthcare services to benefit rural children. For example, a parent advocacy group may convince

influential members of the cabinet that a particular service should be established; an influential section of the media may campaign in favour of a service for rural children, and the cabinet may see it as electorally desirable to comply; members of cabinet from rural electorates may advocate such a service, and may at that time be in a position of strength within cabinet such that their view prevails; the electoral position of a government may depend on retention of rural seats in which a child healthcare facility might be established, or the cabinet may decide that the risks to the government and its insurers, of establishing a facility in a rural area, are less than those of locating the facility only in the city and obliging rural families to travel long distances and frequently to access it. These non-moral reasons, described in section 8.5 as O_m, are depicted in Figure 15 as O_3, an influence on decision-maker M_3.

8.13 Good reasons and morally good reasons

As well as these non-moral reasons for the cabinet to decide to allocate resources in a certain way, and for individual members of cabinet to vote in favour of such an allocation, many RA decisions are made because individual members of cabinet regard those decisions as good in some way. When asked about the features of a decision (e.g. to establish a healthcare program) that would make them regard it as a "good" decision, many of the officials interviewed described features of the process, such as feasibility or the measurability of the outcome of a program or whether the program fulfilled its aims or was based on good evidence. One described aspects of the process which made adoption of that program desirable:

> … *then there was monitoring it to see whether it had achieved its desired outcome, whether it was being spent the way it was intended for so lots of accountability, transparency* … .
> Official 2

As described in section 6.5, some officials were reluctant to agree that ethical considerations played any part in decision-making about healthcare RA or that they were a criterion by which a decision could be judged to be good or bad. Not only were ethical considerations felt by some officials to be irrelevant to decision-making about healthcare RA, but one group of very senior health department officials, having agreed to discuss the subject of the ethical assumptions behind decision-making, decided at the last minute before the discussion began that this was not information that should be shared with the general public, and immediately terminated the interview. That group suggested that the reason for discontinuing discussion was the impossibility, in their view, of ensuring their anonymity. This suggests two things: first, it tends to confirm the subservient and uncritical position of senior public servants, vis à vis ministers, that health advisers described (see section 6.1):

> … *they are very terrified of their ministers or not doing what their minister wants or if this program was the thought bubble of a minister then they can't possibly criticise it because that would look bad, that will reflect badly on them*. Adviser 2

Second, it implies a belief that although health department bureaucrats are nominally servants of the public, and health ministers are elected representatives of the public, the deliberations of these two groups on matters concerning the public should be concealed from that public, whose servants they nominally are. This in turn implies that matters of public good are, in the view of the upper ranks of the civil service, less important than considerations of the re-electability of a government. It also implies a belief (perhaps based on public servants' observations of ministerial behaviour) that ministers are inclined to place more weight on their own limited knowledge of matters concerning their portfolio, obtained during their brief tenure of it, than on the advice of a team of professional public servants long versed in the detail of the department's work, and are more inclined to dismiss public servants with whom they disagree than follow their dissenting advice. The public servants' unwillingness to discuss ethical principles indicates that these are less important determinants of RA decisions than are ministerial impressions, ideas and ideology. One example of this manner of allocation of priorities emerged during an interview:

> *You've got to have one* [policy priority] *that looks at community health and prevention and so on. So, I talked him* [the premier] *into putting one in about preventive health and the one he chose which was very difficult was about reducing childhood obesity*. Official 2

Other officials were prepared to agree that believing that an action was a (morally) good action was a reason to do it, and in this case, believing that a particular healthcare RA was a good allocation was a reason to do it. They described moral motivation of RA decisions this way:

> … *equity is the value that makes a decision morally a good one, at least at the federal level*. Official 7

Section 8.6 discussed the ethical principles which could support healthcare RA decisions in Australia, and indicated that the principle of equality of access to healthcare resources for equal need appeared to be best suit the needs of both rural children and healthcare decision-makers. It appears to suit the needs of decision-makers insofar as "equity" is an avowed aim of federal and state health departments. If the aim of health departments is equity, why is that equity not reflected in the experience of rural families in accessing healthcare for their children or in the health outcomes of rural children? There are several possible reasons for this: first, that the moral reason (the need to achieve "equity" in healthcare RAs) is a nebulous concept and the type of equity (see sections 6.5,

7.5, 7.6 and 8.8) is neither well-defined by health departments nor agreed upon by all decision-makers at all levels of government. Second, the equity that is aimed at appears to be equity from the perspective of the resource allocators, rather than equity from the perspective of consumers (which would take into account health outcomes and experiences of accessing healthcare). Third, centralisation of funding and of decision-making (see section 6.1) militates against rapid adaptation to changing needs in a sparsely distributed rural child population. Fourth, having a moral reason to perform an action such as making an RA decision in a way which achieves equity does not always result in that action being taken. Why that is the case is discussed in the next section.

8.14 How do moral reasons influence action?

From everyday experience, it appears that "people generally feel moved to do what they judge it right to do" (569). For any agent S, judging that he has a moral reason (i.e. that it is morally right) to perform an action favours him performing that action. This sort of reason is termed a motivating reason (570). Other sorts of reasons, such as normative or explanatory reasons, answer the question, posed by an onlooker: "why did she or he do that?" (571). Because the present discussion concerns motivation from the perspective of the agent (e.g. members of cabinet who are to make a decision about healthcare RA) rather than from the point of view of an external observer, it is limited to a description of motivating reasons and their role in decision-making.

It is not the intention in this chapter to canvass all of the theories and sub-theories of the connection between, on the one hand, reasons (factual beliefs about the state of the world) and on the other, causation of an action (569-571), but rather to give an overview of theories of motivation which appear to be relevant to health department officials' decision-making. Any theory which explains the phenomena described by the officials interviewed (Chapter 7) would have to accommodate the fact that moral beliefs (such as: "it is good to allocate healthcare resources in a way that achieves equity of allocation") may be held by decision-makers but do not always lead to decisions which accord with those beliefs.

Statements about moral reasons to make a decision (e.g. "It is right to distribute healthcare resources so as to achieve equity of allocation") can be regarded as propositions in the indicative mood about the world, which can be shown to be true or false (572), or they can be regarded as statements of beliefs held by an agent (where an agent is someone who performs an action). Whether or not such reasons can be shown to be true, the important thing from the perspective of decision-making is that the agent believes them to be true.

According to the theory of internal reasons, having a reason to perform an action always means that one is to some degree motivated to perform that action (571). In Korsgaard's account of moral motivation, an "ideal, rational person" who truly believes that action A is a good action is ipso facto motivated to perform A because it would be irrational not to be so motivated (573). In other accounts, the strength of this motivation (i.e. how likely it is to trump competing motivations to perform a different action) varies from person to person and from time to time. Ruben described these competing motivations as con-reasons, or reasons not to perform action A (574), and are shown as vectors C_{1a}, C_{1b}, C_{2a} C_{2b}, C_{3a} and C_{3b} in Figure 16. Ruben also pointed out that an agent can have a reason to perform an action but may perform that action for some unrelated reason (e.g. I might believe that it is right to allocate funds to a rural medical centre to treat under-served rural children, but the reason that I vote for it is that it will be built in my electorate and I wish to be re-elected in the forthcoming election) (574). This coincidental reason is illustrated as vector O_3 in Figure 15.

In some forms of this theory, the linkage between belief in a reason to perform an action and motivation to perform the action is a necessary one (i.e. if agent X truly believes that it is right to perform action A, then she will always feel motivated to perform A), while in other forms of the theory the linkage is a contingent one (i.e. if agent X believes it is right to perform action A then she will feel motivated to perform A provided condition C is fulfilled) (569).

Svavarsdóttir gave an alternative, externalist view of the relationship between the belief (e.g. that A is a good action) and the motivation to perform action A, noting that "the impact moral judgements have on our deliberations and actions seems to vary a great deal" and

> it seems unrealistic to claim that moral judgements play a pervasive role in the lives of all or even most people. There are considerable variations in how strong a tendency people have to think in moral terms and in how such thoughts affect their decisions and actions. (575)

In rejecting the internalism thesis (that there is a necessary connection between having a reason to perform an action and having motivation to perform that action), Svavarsdóttir pointed out, like J. L. Mackie (576), that moral judgements and the propositions that express them cannot be both truth-evaluable and motivating. She held that the desire (and therefore the motivation) to perform a morally good action is different from, and independent of, the belief that that action is a morally good action. In her view, the motivation to perform a morally good action is a "disposition to be motivated by one's moral judgement" or a "desire to be moral" (575). Svavarsdóttir suggested that this pro-attitude may exist alone, or may be sustained by religious belief and convictions about the

will of God, by a wish to ground one's actions on some objective standards of morality, or by fear of consequences should one fail to do what one believes to be morally correct (575). It may also be sustained by a desire to be the sort of person who acts according to standards that are recognised in the agent's community as morally correct.

Whichever view one takes of the relationship between having a moral reason for performing an action and being motivated to perform that action, one has to acknowledge that belief that an action is a right (or good) action does not always lead the person who holds that belief to perform that action (574). A variety of phenomena may prevent the moral belief from leading to the action which will satisfy that belief. For example, weakness of will or relative powerlessness within the group (e.g. of a cabinet member), lack of opportunity to express one's views, presentation of strong countervailing arguments or fear of adverse consequences for oneself may inhibit the motivation to perform the action. This apparent disconnection between belief and action can be seen in the interviews with decision-makers (Chapter 6). On the one hand, there is the expressed belief in equity as a value that should be pursued in decision-making, but on the other hand, as shown in sections 6.2 and 6.4, political ideology and electoral advantage seem often to be the major determinants of the way in which healthcare resources are allocated in practice. An official described the effect of those political considerations on the range of advice that bureaucrats can offer on allocation decisions:

> *There's a point at which you can actually identify much more rational resource allocation choices, but they're just so politically unacceptable that it's not worth it*. Official 1

While a moral reason for allocating healthcare resources in a way that will lead to equity of RA may exist, either objectively or in the belief of decision-makers, several conditions must be fulfilled in order for that belief to be translated into action (a cabinet decision to allocate the resources in that way). First, enough cabinet members, equipped with enough influence within cabinet, must be motivated to perform the action of voting for that allocation. Then, in the case of individual cabinet members, enough must have a sufficient pro-attitude to that belief to overcome any countervailing influences such as con-reasons or simple indifference. The resultant resolution of cabinet as a whole must be sufficiently firm to overcome countervailing external influences, such as lobbying by pressure groups in favour of some alternative way of spending the money needed to carry out the proposed action, or a media campaign against it. These relationships are expressed in the vector model in Figure 16. The next section discusses how these relationships between having moral reasons to perform an action and being motivated to perform that action apply to decision-makers in Australian health departments.

8.15 What prevents health departments' intentions to ameliorate rural child health and wellbeing from being carried out?

The answer to this question may be found in sections 6.3, 6.4 and 8.5, and Figure 16. Looking at the question of "what is a right action" from the point of view of an individual who contributes to a group decision (e.g. a cabinet decision to allocate a healthcare resource with the aim of improving the health and wellbeing of rural children), that individual may have a moral reason to vote within the group for the allocation to be made. She may or may not be aware of that reason. Assuming that she is aware of it, whether she does or does not vote for that allocation (in other words, whether her moral reason is translated into the act of voting for the allocation) will depend on her motivation. If that motivation is insufficiently strong, and if she has con-reasons (see section 8.11) against voting for the allocation, she will not vote for it. If several members of the group (especially influential members) are in this situation, despite the fact that they judge that there is a moral reason to vote to make the allocation, the net result will be that the allocation is not made.

8.16 Summary

Rural children are a disadvantaged group compared with urban children in Australian terms, but that disadvantage is less apparent in global terms. Equity offers an ethical framework for distributing healthcare resources that ameliorates their disadvantage that is more defensible than other ethical frameworks such as utilitarian principles or children's rights . The case for regarding rural children as disadvantaged is based on their worse health outcomes than urban children, and on the greater difficulty their families experience in obtaining healthcare for them than urban families. Rural children share with their urban counterparts their dependence on adults for accessing healthcare. When combined with location of domicile distant from healthcare resources, this magnifies their relative disadvantage. Acknowledgement by government decision-makers of the ethical requirement to distribute healthcare resources in a way that will improve the wellbeing of the disadvantaged (in this case, rural children) more than any other pattern of RA is the ethical principle which is most likely to satisfy the needs of rural children for action to maximise their welfare, and the needs of government decision-makers to act according to a principle which they acknowledge.

Some Australian federal and state health department officials recognise this disadvantage, and that there is a case for extra consideration to be given to rural persons and to rural children in the name of equity and in order to give extra consideration to the needs of the disadvantaged. Despite this awareness, the disadvantage persists; why?

Several answers to this question can be posited. First, the failure of decision-makers to agree on the type of equity which they are aiming to attain. Second, the persistence of the view that equity should be seen from the viewpoint of decision-makers rather than from the viewpoint of consumers (i.e. from the viewpoint of patients or potential patients, including rural families). Third, the officials who contribute to RA decisions within health departments may have insufficient motivation to act on a moral reason of which they *are* aware.

Chapter 9 Overall summary

Health is important. The health of children is important to the individual child because health is necessary (though not sufficient) for a child to become a moral agent and thereby to develop agency to pursue those life plans that he or she comes (as an adult) to value. There are several contributors to the health of rural children, especially social contributors, but healthcare also plays a role in health outcomes. Evidence clearly shows that the health status and health outcomes of rural children are less favourable than those of urban children.

9.1 The disadvantage of rural children in health and healthcare

There are several aspects to the health disadvantage of rural children. First, there are those aspects of the social determinants of health, such as poverty, low parental educational attainment and poor housing, which are not remediable by improvement in healthcare access, although they may be remediable (at least to some extent) by other actions of government, including actions to coordinate the activities of government agencies. Second, there are disadvantages in health outcome (compared with the health outcomes of urban children) which are due to the different epidemiology of childhood illness in rural areas (see section 1.8). Third, there are the disadvantages of being a child (described in section 1.11) which limit his ability to gain access to healthcare without adult assistance and which determine his site of domicile (e.g. in a region remote from healthcare and other resources) without reference to his wishes. Further, being a child, and therefore dependent, attaches the child to a family and to its disadvantages of poverty, poor education, poor housing, etc., all of which, in Australia, are found more commonly among rural families. As described later in this chapter, this underlying disadvantage is relevant to the consideration of the appropriate healthcare framework to guide RA which affects these children.

As described in section 1.7, healthcare has a role in determining health outcomes (given that as healthcare has improved, overall health outcomes and outcomes of individual illnesses have also continued to improve). Since there is evidence that rural children have less access to healthcare than urban children (as Chapter 5 and section 8.1 demonstrate) and have less favourable health outcomes than urban children, it appears likely that their disadvantage in access to healthcare contributes to those worse outcomes. It is, of course, not possible to conduct a randomised controlled trial of the effect of access to healthcare on health outcomes in order to gain more convincing evidence of this hypothesis.

Chapter 5 presented data showing that several aspects of access to healthcare for children were experienced as unsatisfactory significantly more often by rural than urban families. This indicates

relative perceived disadvantage in access. What the survey asked about, though – and therefore what individual families reported – were incidences of *absolute* disadvantage in healthcare access (compared with what that family would regard as ideal or satisfactory or even adequate). The distinction between relative and absolute disadvantage is important for the consideration of the appropriate ethical framework to guide the allocation of healthcare resources, as discussed later in this chapter. These absolute disadvantages in healthcare access of rural children are also described in sections 8.1 and 8.6.

9.2 The effect of government decisions on the healthcare disadvantage of rural children

The absolute healthcare disadvantage of an individual rural child is determined by several factors: the particular healthcare resources which that child needs to attain her or his optimal health outcome; what relevant healthcare resources are available; their quality relevant to the child's needs, and their geographical remoteness from the child. The nature, quality and location of healthcare resources available to rural children are (potentially) under the control of government (federal, state or local, in Australia), although no single level of government has complete control over resource availability, and some resources such as GP services and some allied health services are supplied by private providers (see Chapter 5 and Appendix 4). Chapter 6 examined the structure of power within Australian health departments from the point of view of senior officials, and concluded that the ultimate power to make decisions about what healthcare resources would be allocated, and where they would be placed, lay with politicians. The role of even senior bureaucrats was to offer advice on such allocation, but given their propensity (reported in Chapter 6) to give advice only in conformity with the ideological position and the electoral interests of government ministers, their scope for offering advice in accordance with some ethical principle or other appears limited.

9.3 The views of government officials on healthcare resource allocation decision-making

As the role of the Australian Government in health appears (as reported by interviewees; see Chapter 6) to be one of distributing funds on a macro scale without examination of the interests of, or the effects on, individuals or small groups of individuals, most capability to make RA decisions which reduce the disadvantage of rural children in access to healthcare rests with state health departments. One exception to this is the PBS, in which decisions made at federal level to subsidise (or not) an individual expensive medication affect patients who require that medication. This does

not necessarily distribute funds from urban to rural patients, though in some cases it may distribute funds towards children (e.g. by subsidising a drug to treat a disease like spinal muscular atrophy type 1 which affects children but not adults). Within state health departments, as section 6.1 and Kirigia (2009) (265) showed, the power to distribute funds according to an ethical principle rests with departmental head office personnel rather than regional staff. In general, then, most power to allocate healthcare resources which affect rural children lies with state politicians, and in particular with members of cabinet in each state.

Interviewees described (section 6.2) the various aims of RA decisions, such as satisfying identified healthcare needs (of the community as a whole and of subsections of the community, such as rural persons). Other aims mentioned by interviewees included keeping the health department's expenditure within its allocated budget; obtaining the best overall improvement in population health for the money spent; fulfilling the pre-election promises made to the electorate (as a whole, and to individual electorates); to allocate resources so as to obtain the best social outcome, such as the preservation of rural and regional towns; and finally, ensuring that the decision-making process is transparent, is supported by evidence and has measurable and reportable outcomes. As noted in section 6.2, several of these avowed aims are incompatible with each other and with the ethical aim, claimed by several of the officials interviewed, of achieving equity (discussed below) in RA.

Although evidence of healthcare need and evidence of the efficacy of a healthcare program were said by interviewees to be important factors in decisions about allocation of funds, evidence appeared (according to several interviewees) to play a smaller role in decision-making than was claimed. Moreover, for rural children with sporadically occurring illness in a sparse population, need is difficult to measure and to document in a way that supports allocation of resources to them. Keeping expenditure within budget and making RAs which favoured re-election of the government seemed (according to interviewees) to be dominant underlying aims, while the utilitarian aim of obtaining the best overall health gain for the money spent was an important background aim. Interviewees displayed an ambivalent attitude both towards rural persons and towards children and to the groups which lobby on their behalf (see Chapter 6) when considering whether each group should receive extra consideration in the allocation of healthcare resources to compensate for disadvantage in access to healthcare.

Interviewees reported that there were several constraints on their ability to make RA decisions which might benefit rural children. Apart from the financial and political constraints just mentioned, there were several limitations on their ability to allocate services in rural areas for the benefit of the rural population (see Chapter 6). The higher cost of locating services in rural or regional towns was a

major obstacle, given the underlying aims of keeping expenditure within departmental budget and obtaining the best overall gain in population health for the money spent. Risk aversion and avoidance of adverse publicity about poorer health outcomes in low-volume health services reduced the likelihood that complex services such as paediatric surgery and obstetrics would be located in rural and regional centres. Finally, difficulty in placing appropriately trained and experienced staff in rural or regional towns limited decision-makers' ability to locate specialist services (including specialist paediatric services) there.

9.4 The role of ethics in resource allocation decision-making

As described in section 6.5, officials were reluctant to accord an important role to ethical principles in the making of RA decisions. Both the Federal and NSW Departments of Health have published policy documents (enshrined in law in the federal case), requiring staff to make RA decisions in accordance with the principle of equity. The NSW document discusses the various aspects of equity in some detail, but while officials agreed during interviews that they should be aiming to achieve equity in their RAs (and indeed that they should achieve vertical equity; that is, allocation decisions should be made in a way that gave extra benefit to the more disadvantaged – see section 6.5), there did not appear to be agreement on whether the sort of equity that was aimed for (and the sort of inequity which should be compensated for) should be equity in RA, equity in access to healthcare services or equity in health. As discussed in section 6.5, the grounds for adopting a principle of equity in RA appeared to be *noblesse oblige*, rather than the Rawlsian grounds of "if I were behind a veil of ignorance and unaware of whether I was a rural child or not, I would want resources to be distributed according to a principle of equity." Indeed, the Rawlsian rationale for aiming to achieve equity was specifically dismissed by one official. Similarly, the fact that governors and governed are members of the same community and therefore share mutual obligations did not appear to be the reason why interviewees espoused the principle of equity in RA. Interviewees also addressed the principle of rights of rural children to healthcare only to dismiss it (section 6.5).

9.5 What ethical framework might reduce the rural child's healthcare disadvantage?

The ethical frameworks which *could* guide healthcare RA decision-making are described in Chapter 7. Of these, libertarianism can be eliminated first, because allocation according to libertarian principles would be likely to worsen the current healthcare disadvantage of rural children, and certainly could not reduce the disadvantage since, according to its principles, each individual is responsible for his or her own healthcare, and rural families are already more likely to be socioeconomically and

educationally disadvantaged than urban families. Second, libertarian principles appear not to be compatible with Australian values expressed in surveys (311, 313) and by interviewees (see sections 6.2 and 6.5).

Distributing healthcare resources according to the putative rights (discussed in sections 7.11 and 8.12) of children does not appear to be a reliable way of reducing either the relative or the absolute healthcare disadvantage of rural children. As the discussion of rights in section 7.11 concludes, the existence of a right depends on the validity of the argument which justifies it. An assertion of a natural right, such as those set out in the UN Convention on the Rights of the Child (415), can be just as validly denied as it can be asserted. This point becomes clearer if one regards rights statements as grammatically imperative rather than indicative. In the absence of a valid argument justifying the rights statement as a statement about the state of the world, that statement reduces to an injunction to confer a right, such as "let every child have a right to healthcare," which can be simply denied.

Deontological arguments for rights support a qualitative conception of rights (e.g. this right to a benefit exists) without specifying the amount of that benefit to which the right-holder has a claim. This could mean, for example, that a rural child might have a right (supported by the deontological argument) only to some minimal amount of healthcare which could be insufficient to overcome the child's healthcare disadvantage (see sections 1.8 and 8.1). Section 8.12 also points out that the utilitarian argument for rights reduces to rule consequentialism, which cannot support actions needed to compensate for the healthcare disadvantage of rural children. Although the contractarian argument for the existence of rights appears to be the most plausible account of rights, it reduces to a Rawlsian argument for justice, which in turn makes the concept of a right redundant. As with the deontological argument for rights, discussed above, the contractarian argument supports a qualitative concept of a right without supplying any guidance about the *amount* of the benefit to which the right-holder has a claim. Thus, the concept of a right to healthcare is unreliable as a support for an argument for better access to healthcare for rural children. The existence of rights is debatable, and even if they existed, they would provide only weak support for an argument for better access to healthcare for rural children.

The commonsense empirical principle of supplying the identified healthcare needs of the population shares the practical problem of all ethics-based funding principles: they support prospective RAs. This carries the risk that differences between predicted use and actual use of a service can lead to large financial deficits for a health department. As pointed out in sections 6.2, 6.3 and 7.3, RA to satisfy the healthcare needs of rural children is difficult to achieve with the current large-scale

methods of needs-based funding. This is because the rural child population is sparsely distributed and its healthcare needs are heterogeneous and appear sporadically, especially in the case of children with complex care needs. This means that in order to meet the true needs of this population, the funding and allocation system must be flexible and rapidly responsive to newly arising needs, and illness monitoring must supply information that allows RA to occur in real time. A change to the RA system to allow this to occur would require a moral reason to make the change, and as described later in this chapter, the motivation to make the change required by that moral reason.

The two metaethical principles which are most likely to be able to guide healthcare RA in Australia are utilitarianism and equity. The roles of communitarianism, compassion and solidarity are discussed later in this chapter. Utilitarianism, described in section 7.4, judges the goodness of a healthcare RA decision by its net benefit (sum of all benefits minus the sum all harms) to all of those affected by it. When it is used as a guiding principle, likely benefits and harms must be assessed prospectively, based on whatever information on needs, numbers of persons with those needs and the efficacy of healthcare programs which can supply those needs is currently available. The problem of judging goodness according to the net benefit (e.g. of a healthcare program) is that a program which benefits the largest proportion of the population (e.g. city dwellers in Australia, where the largest proportion of the population lives in cities, or adults, who form more than 80% of the Australian population) could be judged a good one on utilitarian grounds because the greatest overall benefit was anticipated, although it may allocate little or nothing to minority groups like rural dwellers or children. If utilitarian principles operate, but with side constraints (see section 7.3) such as the obligation to achieve equity between city dwellers and country dwellers operating to minimise the ill effects of judging goodness according to net benefit, then observance of these side constraints becomes the criterion by which the goodness of the RA is judged.

A significant problem for utilitarianism is identification of benefits and harms. It is generally agreed that the most appropriate person to judge the benefits and harms of an action is the person who experiences them. An example of this is the use of quality of life indices summed across populations to assess the net benefit of a healthcare program. In the case of a child, however (see section 2.4), the valuation of a health state varies with the stage of life and with the individual's experiences and life circumstances. In children, preferences and valuation of health states can vary from day to day. In younger children, there is the additional problem that they cannot express outcome preferences or their valuation of their health state, so RA decision-makers (at the level of clinicians, institutional managers or health department officials) rely on proxy estimation by the child's parents of the

child's preferences. These estimates may be contaminated by the preferences of the parents and by the parents' estimates of the best interests of the family or of the child's siblings.

When no reliable estimates of health or healthcare preferences of a population are available to the decision-makers, they must make assumptions about those preferences. These assumptions may not reflect the preferences of the population in question and must inevitably be paternalistic, in that they reflect the decision-makers' cultural assumptions and perceptions of the population and its preferences. Even when a sample of expressed preferences is available to decision-makers (e.g. by means of a survey), that sample may not be representative of parts of the population, or even (depending on sample size and population heterogeneity) of the whole population, and if assumed preferences or the preferences of a surveyed population sample are used to guide decision-making, there will be some individuals whose preferences the decision does not satisfy. This is a particular problem for rural children – a sparse population of individuals of a range of ages and with a variety of health states and socioeconomic circumstances. For all of these reasons, the use of utilitarian principles to guide the allocation of healthcare resources that affect rural children is quite unlikely to address their healthcare disadvantage.

The most obvious alternative ethical principle to utilitarianism to guide RA decisions is some form of equity. The concepts of equality (a descriptive term) and equity (its normative counterpart) were described in sections 7.5 and 7.6. As noted there, there are several grounds for supporting the achievement of equality/equity as the criterion by which the goodness of an action such as a healthcare RA can be judged. These include contractarian, Kantian, utilitarian and Rawlsian grounds (section 7.12), but it can also be supported on communitarian and solidarity grounds and on the grounds of compassion, as described later in this chapter.

Mooney (2003) discussed the various aspects of a healthcare RA, equity which might be the criterion by which the goodness of that allocation might be judged (453). For whole-of-government RA, equity in health may be the most appropriate criterion. As described in sections 6.2 and 6.4, this may be regarded more as an ideal to be pursued when the opportunity arises, rather than as a rigid criterion by which goodness is judged. The problem with regarding it in this way is that it permits a government to claim that while health equity is its goal, circumstances just haven't been quite right to permit the actions needed to achieve that goal. As will be pointed out later in this chapter, that is part of the problem which has allowed the current disparity in health and in healthcare access between rural and urban children to persist.

For a health department which controls the allocation of healthcare resources but has little control over allocations which influence the social determinants of health, the criterion of equality of

opportunity for access for equal healthcare need (see section 7.4) is a more appropriate criterion by which to judge the goodness of an RA decision. The problems with this criterion, as section 7.4 pointed out, are first, that comparison of the magnitude and nature of the healthcare needs of different population groups (such as infants, the elderly, the disabled and those with different types of illness) is difficult. The second problem is: who is to make the comparison and by what criteria? The best judges of need are the individual and his or her clinician, but that individual cannot judge the needs of others. The problem with estimating the healthcare needs of children has been pointed out above.

Despite these difficulties, equality of opportunity for access to healthcare for equal healthcare need (however estimated) appears to offer the best and most practicable criterion for judging the goodness of a healthcare allocation. As both Federal and NSW Government documents support equity as a criterion for judging the goodness of healthcare allocations and stipulate that allocations should be made in a way that achieves equity, why is it that rural children experience such disadvantage in health (described in Chapter 1) and in healthcare (described in Chapter 5 and in Chapter 8)? Several reasons contribute to this. First, as described in Chapter 6, health department decision-makers do not share a common vision of the type of equity which they are aiming to achieve in their decision-making. While some emphasised equity in allocation of resources, others stated that they were aiming to achieve equity in access to healthcare resources, and some at times appeared to be advocating equity in health as the goal of a health department decision-maker. While each of these is a laudable goal, lack of consensus on the ethical criterion by which the goodness of decisions is judged militates against the use of any of those criteria. Clarity of thinking about the type of equity to be aimed at is likely to focus more accurately the measures required to achieve that equity.

The second contributing factor lies in decision-makers' degree of motivation to base their actions (such as taking or advocating a certain course of action, such as deciding to allocate a healthcare resource in a way which would benefit rural children) on an ethical belief which they hold. The topic of moral motivation is discussed in Chapter 8. When constraints such as political or financial considerations operate as powerful con-reasons (see section 8.8), the motivation to act according to an ethical belief must be very strong in order to overcome them. As noted already, most decision-making power lies in the hands of members of federal or state cabinet, who are politicians. The nature of politics inevitably involves compromise, and the ubiquity of compromise in day-to-day dealings of cabinet members is likely to militate against the motivational force of any ethical belief when there are important countervailing practical considerations such as the limitations of a budget or the re-electability of a government.

As pointed out in section 8.12, the ethical tradition which has prevailed in anglophone countries (which includes Australia) since the time of Thomas Hobbes has been the primacy of the individual. That tradition underlies the arguments of John Rawls for justice as equity as well as the tradition of the social contract. The European tradition of communitarianism and solidarity (described in section 8.12), expressed most clearly in the philosophical literature of Germany and Holland, emphasises the moral importance of being part of a community. Apart from underpinning the intellectual content of meta-ethical principles such as equity, the concept that one's membership of a community imposes obligations on one to further the interests of other members of that community also supplies motivation to act on those obligations. We, in Australia, are also members of communities (the human race, the citizens of Australia, residents of our state as well as other sub-communities). Politicians, including the Cabinet ministers who make healthcare RA decisions, are also members of those communities and, whether they are aware of it or not, share the obligations to other members of those communities which community membership entails. An important contributor to the evident inefficacy of moral reasons such as equity to guide RA decisions appears to be insufficiency of motivation to act according to those moral reasons. It seems likely then, that recognition by healthcare RA decision-makers that we (including city and country dwellers, adults and children) are all part of a community and that that fact imposes obligations on all of us towards each other, including to treat other members of the community equitably, would supply the motivation (described in Section 8.8) needed to act according to the principles which Government health departments claim to espouse.

9.6 How might the issues of service incoordination and failure to act according to an avowed moral belief be addressed?

The findings and analysis described in chapter 8 point to some measures which might alleviate the disadvantage in health and in healthcare access experienced by children in rural and remote areas of Australia. Several interventions could be suggested to increase the motivation of decision-makers to act on a moral belief that RA decisions should aim to achieve equity despite con-reasons such as considerations of budgetary limits, requirements to obtain best overall health outcomes for financial outlay, risk aversion, workforce difficulties and political requirements. Each of the interventions suggested below is aimed at overcoming one or more of the barriers to acting on moral belief.

First, health departments themselves could conduct further studies on what sort of equity is being aimed at (see section 7.5) and on what "equity" would look like from the point of view of rural children and their families. In particular, health departments could consider how re-organisation of

their functions might achieve equity without extra financial outlay. These overall goals may require several intermediate steps:

1. Publicity to increase awareness in the general public about the real disadvantage of rural children (and thereby increase the electoral motivation of elected decision-makers and their advisers), plus specific education of those decision-makers could increase the moral motivation of decision-makers to achieve equity in healthcare RA.
2. Education of that same group on what true vertical equity might entail in the allocation of healthcare resources to rural children, given the family experiences described in chapter 5 and section 8.1.
3. Better coordination of information and services. This is a function of state health departments, since no other level of government has both the breadth of overview and the authority to make the changes necessary to ensure that services are coordinated.
    a. Careful coordination of services at all government and service delivery levels:
        i. coordination of federal and state services;
        ii. coordination of whole-of-government services at state level. This should not be just token coordination or co-location, but requires close control from a high level within the state government. For example, the Department of Premier and Cabinet has the authority to ensure that functions of the Departments of Health, Education, Transport and Social Services mesh closely with each other. This requires close supervision, monitoring of meaningful outcomes (not just statistics), and action to ensure that outcomes of individual children are optimised;
        iii. coordination between, on one hand, the activities of hospitals and health centres, and on the other, the activities of other government instrumentalities; and
        iv. coordination of government services with private health providers such as general practitioners and allied health providers.
    b. Establishment of a system of case managers with access to databases of healthcare, transport, education and social service resources and the ability to travel and coordinate all aspects of care of individual children and of their families. This means acting as the coordinator, for an individual child, of all of the functions mentioned in 3a above, as well as those of parent education, well child visits and home visiting services. At present, this role is in theory performed by the child's parents and by the family's GP. In practice, however, parents are not always aware of what services

exist that are relevant to their child's care and are not always capable of navigating the maze of applications needed to access them. GPs are not always readily available in rural areas, nor do they always have the time nor the resources needed to find and coordinate access to services needed by an individual child.

It could be argued that respect for the autonomy of the child's parents requires that the task of selecting and coordinating services be left to them. Given the child's limited capabilities and the family interests which compete with the child's own, described in section 1.13, however, respect for parent autonomy should be subordinate to consideration of the wellbeing of the disadvantaged child.

9.7 In Conclusion

Health is important, first as a good in itself, as a component of wellbeing, and instrumentally as a necessary condition of agency and of the capability to pursue one's life goals. It is known that children living in rural and remote areas of Australia have worse health outcomes, both in infant mortality and in morbidity from a variety of illnesses, including ACSCs, than urban children. This disparity in outcomes increases with remoteness of domicile. Although social determinants are major contributors to health status, healthcare is also a significant contributor, and differences in access to healthcare appear to be significant contributors to differences in health between rural children and urban children.

Access to healthcare for rural children depends, in each of the domains of access, on the location and nature of the healthcare resources which the child needs. This is especially problematic for children with chronic illness and for those with complex healthcare needs, but that is also the case for children with acute illnesses such as trauma or severe gastroenteritis. The nature and location of healthcare facilities depends on RA decisions by government health departments. Even the location and nature of services provided by private clinicians is affected to some extent by government decisions.

This research aimed to answer the following questions:

1. What healthcare resources are currently available for children in rural and remote areas in Australia?
2. How do parents experience the provision of healthcare resources for their children and the consequences for their child and family of that pattern of resource provision?
3. How are healthcare resources allocated to rural children and what factors are considered in making this allocation?

4. What ethical framework underpins the allocation of healthcare resources for children now?
5. What ethical framework may guide healthcare resource allocation for children in a way that best fits the needs of rural children, of their families and of government health officials?

To answer question 1, data were obtained on the geographic location of health services required by children living in communities of various sizes in Western NSW. This investigation showed that child-relevant facilities were lacking in a large proportion of rural communities.

To answer question 2, data from the NSWCPHS 2011–14 were analysed. These showed that rural parents (especially those in more remote areas of the state) were more likely than urban parents to report difficulty in obtaining access to healthcare for their child. These difficulties included problems in access to GPs and specialists, lack of health facilities in their area and problems with EDs (Section 5.2).

For questions 3 and 4, officials of the Australian Federal and NSW Departments of Health were interviewed. Data from the interviews showed that effectively, the RA decision-makers in both jurisdictions were politicians (members of cabinet), though bureaucrats made choices on the advice which they offered to inform cabinet decisions. Availability of funds and risk aversion constrained the decisions on allocation of resources to rural areas. The need to obtain best overall health outcomes for the money spent was felt to be a background consideration rather than a major aim. Participants agreed that resources should be allocated so as to achieve equity, but there was little agreement on whether the equity to be achieved was equity in RA or in access to healthcare or in health outcomes. Participants did not feel that children's dependence on others meant that they should receive extra consideration in RA, and participants were ambivalent about according extra resources to rural persons (Chapter 6).

To answer question 5, the metaethical principles which *could* guide RA decisions were explored in Chapter 7. In Chapter 8, the suitability of each of these was assessed. It was concluded that the most suitable guiding principle was vertical equity (favouring the most disadvantaged) in allocation of resources for equal need. Further, it was concluded that the failure of current ethical principles to achieve equity in health outcomes or in families' experience of accessing healthcare for children was due to several factors. These included failure to agree on what sort of equity should be aimed at; failure to consider equity from the viewpoint of the consumer (i.e. the patient or the patient's family); failure to consider coordination of services as part of RA; and inadequacy of motivation to act so as to achieve equity in the face of competing aims, such as political goals.

9.8 Limitations of this study

The limitations of the current study were the low rates of recruitment of decision-makers and of parents of rural children. Interview fatigue (after participation in multiple studies) and perhaps fear of compromising their own employment may have contributed to the reluctance of decision-makers to be interviewed, while rural parents may have seen no benefit to themselves or their children in participation and, despite assurance of anonymity, may have been wary of compromising their relationship with their child's clinicians.

Other limitations were imposed by restriction of the study to one Australian state, due to the limits on what could be achieved by a single investigator in the time available in a PhD study. To determine whether the findings of this study apply to other states, further studies should be undertaken in those states.

9.9 Opportunities for further research

Further research in this area should examine the understanding of decision-makers of the meaning of equity and of its dimensions, and on the magnitude of their motivation to achieve ethical goals compared with their motivation to achieve other goals. Other areas of research include feasibility studies on the financial, logistic and workforce implications of instituting a system of mobile case managers across rural and remote areas of an Australian state.

As one of the interviewees noted, no public conversations had been undertaken on the question of limiting expenditure on the most expensive treatments to divert those funds to alleviate healthcare disadvantage elsewhere. Large-scale public consultation may elucidate this issue.

9.10 Finally

Finally, what has been the contribution of this study to knowledge? First, no other study has examined the location of healthcare services for children in relation to the location of rural child populations of various sizes in Australia. Second, no other study has compared the ability of different meta-ethical principles to reduce health disadvantage when applied to the healthcare of rural children. Third, no other study has examined the role of moral motivation in creation of the discrepancy between avowed ethical belief and action on that belief in the context of allocation of healthcare to rural children. Fourth, no other study has examined the obligations of a democratically-elected government to overcome the health disadvantage of rural children, given their capability disadvantage. Fifth, no other study has examined the ethical principles, according to which allocation of healthcare resources to rural children in Australia are made in practice.

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Appendix 1: Australian Bureau of Statistics Remoteness Areas Classification: ASGS

The Australian Statistical Geography Standard (ASGS) 2011 classifies all parts of Australia into seven remoteness categories (Table 21).

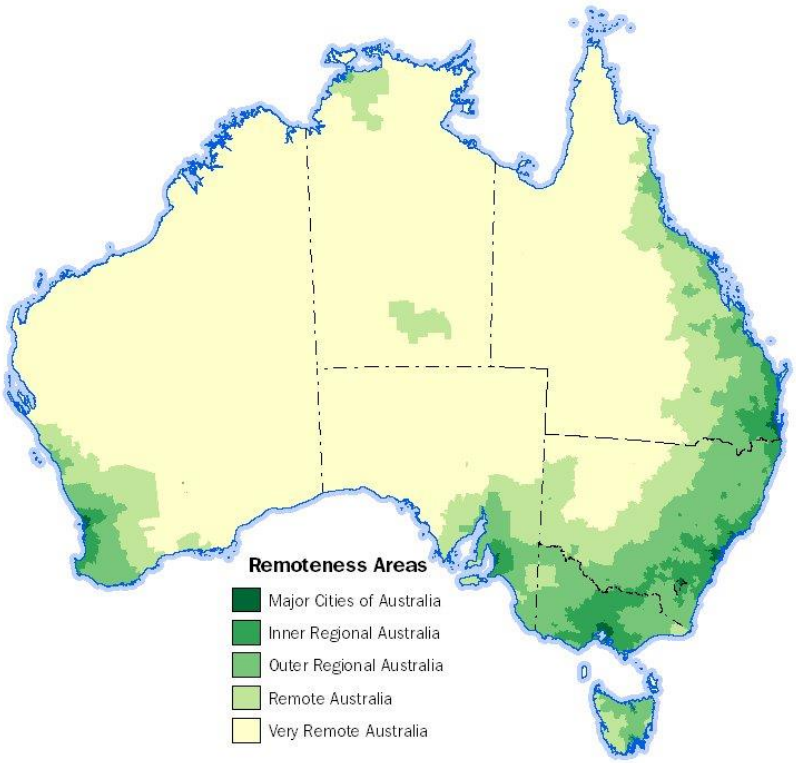
TABLE 21 REMOTENESS AREAS OF AUSTRALIA BY ARIA + VALUE

Remoteness area category	Remoteness area name	SA1 average ARIA+ value range
0	Major cities of Australia	0 – 0.2
1	Inner Regional Australia	>0.2 and ≤ 2.4
2	Outer Regional Australia	>2.4 and ≤ 5.92
3	Remote Australia	>5.92 and ≤10.53
4	Very Remote Australia	>10.53
5	Migratory – Offshore – Shipping	
9	No usual address	

Data from the Australian Statistical Geography Standard (ASGS) Volume 1(577)

The ASGS divides Australia into 54,805 small geographical units, known as Statistical Local Area 1s (SA1s), each with an average population of 400 (range 200–800, those in rural areas having the smaller populations (577). The Hugo Centre for Migration and Population Research at the University of Adelaide produces a remoteness index known as ARIA+ (Accessibility/Remoteness Index of Australia). In ARIA+, a one-kilometre grid covers all of Australia. Each point on the grid is given an ARIA+ value between zero and 15, based on a standardised function of road distances from that point to the nearest service centre in each of five classes of population size (578). Each SA1 contains several of these grid points, whose ARIA+ score is combined to give an average ARIA+ score for that SA1 (577). Table 21 shows how those average ARIA+ scores are used to categorise areas of Australia as one of five remoteness classes (see Figure 16).

FIGURE 17 REMOTENESS AREAS OF AUSTRALIA



Adapted from ABS (2018): the Australian Statistical Geography Standard Remoteness Structure (579)

Appendix 2: Morbidity in rural children

Injury

Injury is the leading cause of death in children aged 1–14 years in Australia (82), New Zealand (580), Canada (581), the US (582) and all other Organisation for Economic Cooperation and Development countries. Rural Children in NSW under the age of 5 years are twice as likely to die from trauma as their urban counterparts (583) and rural children of all ages in NSW are more than twice as likely as their urban counterparts to be hospitalised because of motor vehicle trauma (584). Each year on average 575 Australian children are admitted to hospital because of farm-related injury and 30 of those die (585). The main causes of these injuries and deaths are drowning in farm dams or other water bodies, accidents involving equipment, especially tractors or quad bikes, falls and accidents involving large animals. Australian children in rural and remote areas are also more likely than urban children to suffer burn injuries (586) or sports-related injuries (587). These findings reflect the epidemiology of road trauma in rural children in Australia. The likelihood of dying after major trauma, however, increases with distance from the nearest hospital (588), a finding which reflects the effect of remoteness on access to healthcare. To minimise this aspect of the health disadvantage of remoteness, a healthcare system must be responsive to acute need.

Infection

Children in rural and remote areas of Australia are at least 25% more likely than their urban counterparts (70% more likely in the case of Indigenous children) to require hospital admission because of infection. These infections are most commonly respiratory (including otitis media), gastrointestinal or perinatal infections or infections of the urinary tract or skin (589).

In some cases there appears to be an interaction between living conditions, nutritional state, ethnicity and contact with animals which influences the infections that are experienced, especially when these involve respiratory infection or carriage of gastrointestinal parasites (589, 590). In rural areas where access to primary care is difficult, children with infectious disease are likely to present late, with more advanced illness, and are therefore more likely to suffer prolonged illness and to require hospital care than children in urban areas where primary care is more accessible (591).

Cancer

Children in rural and remote Australia are 21% less likely to be diagnosed with cancer than their urban counterparts (principally because of the lower incidence of cancer in Indigenous people than in non-Indigenous) (592). Youlden et al. (2011) found that children in inner and outer regional areas of Australia as well as rural and remote areas who *do* suffer from cancer, however, have a

significantly greater likelihood of dying of the cancer than children in metropolitan areas (593). These findings were similar in non-Indigenous and Indigenous children. These authors noted that difficulties in access (594) and the financial burden (595, 596) and disruption of family life caused by travel to distant centres for diagnosis and ongoing treatment of a child with cancer may contribute to this rural disadvantage in outcome (593).

Suicide and mental health

Suicide is an important cause of death in older children and adolescents in Australia, often in children known to have mental health or behavioural problems, family conflicts or a history of physical, sexual or emotional abuse (597). In Queensland between 2000 and 2010, suicide was much more common in children aged 14 years or younger living in rural or remote areas than in urban children. This was the case both in Indigenous and non-Indigenous children, although suicide was 12 times more prevalent in Indigenous children than in non-Indigenous (598). In the 2015 Second Australian Child and Adolescent Survey of Mental Health and Wellbeing, more rural than metropolitan children reported having had a mental disorder of some kind in the last 12 months. This difference was much greater in boys, with almost 20% of rural boys reporting having had some kind of mental disorder in the last 12 months (599). Several factors may lead to the higher incidence of youth suicide in rural children and adolescents, including social isolation, same-sex attractedness, and unemployment but also difficulty in accessing adequate mental healthcare in rural areas (600, 601).

Respiratory illnesses

The commonest forms of respiratory illness in Australian children, including rural children, are asthma, bronchiolitis and community-acquired pneumonia.

ASTHMA

Australian studies have found considerable variability in the prevalence of childhood asthma between rural areas (602-605). Children over the age of three years in remote and very remote areas are significantly more likely to have asthma currently, or to have had it previously, than urban children (606). Children from rural areas with high levels of industrial atmospheric pollution are more likely to wheeze than urban children or children from rural coastal areas (603). These findings reflect the epidemiology of childhood asthma. Children in Australia are significantly more likely to require admission to hospital because of asthma if they live in a city than if they live in non-metropolitan areas, but if rural children require hospital admission because of asthma, they tend to have a significantly longer hospital stay, especially those from inner regional and very remote areas (47). The adequacy and accessibility of primary care of asthmatic children may contribute to this

difference in length of stay, because the later in an acute asthma attack that treatment is started, the more likely are mucus plugs to form in small airways, greatly slowing recovery from the attack.

BRONCHIOLITIS

Acute bronchiolitis is a common viral respiratory illness which causes wheezing and severe respiratory distress in infants. In Australia, hospital admission of infants in NSW in 1992–97 for acute bronchiolitis was significantly more common in rural areas (56 per 1,000 population) than in urban areas (41 per 1,000) (48).

COMMUNITY-ACQUIRED PNEUMONIA

Several groups, especially from Australia, Canada and the US, have reported that lower respiratory infection is more common in rural children than in urban children, especially in those less than one year of age (607-610). In NSW in 2009–10, the number of children 0–4 years old admitted to hospital because of influenza or pneumonia per 100,000 children increased progressively with increasing remoteness from major cities (Table 24). When access to primary care is difficult, treatment of respiratory illness may not start until the illness is more advanced, so that the child is more likely to require hospital admission and the hospital stay is likely to be more prolonged than if treatment had commenced earlier. The higher hospitalisation rate of rural children with respiratory illness may be due to their greater difficulty in accessing primary healthcare (see section 1.14 and Chapter 5).

In a smaller series, Moore et al., studying all singleton live births in the state of Western Australia in 1999–2000, found that pneumonia and bronchitis occurred 1.4 to 6.6 times more commonly in 0–2-year-olds in rural or remote areas than in the metropolitan area. This finding applied both to Indigenous and to non-Indigenous children, although the incidence in Indigenous children was significantly greater than that in non-Indigenous (611).

TABLE 22 HOSPITALISATIONS OF NSW CHILDREN FOR INFLUENZA OR PNEUMONIA BY REMOTENESS FROM SERVICE CENTRES, 2009–10

Remoteness Area	Hospitalisations per 100,000 population
Major cities	543.9
Inner regional	605
Outer regional	626.2
Remote	1173.1

Health Statistics NSW (2011) (610)

Appendix 3: Geographical distribution of the Australian child population

Australia's population of children aged 0–15 years increased by 33.7% over 50 years from 3,419,710 in 1966 to 4,572,597 in 2016 (612). In 2006, 66% of children lived in Major Cities, 21% in Inner Regional areas, 10% in Outer Regional areas, 1.8% in Remote and 1.1% in Very Remote areas (613).

Indigenous children made up 4.8% of all Australian children aged 0–14 years and 38% of all children living in remote and very remote areas in 2006 (614). See Table 22.

TABLE 23 DISTRIBUTION OF INDIGENOUS CHILDREN AND ALL CHILDREN AGED 0–14 YEARS BY LEVEL OF REMOTENESS, 2006

	Indigenous children	All children
Major cities	31.7%	66.0%
Inner regional	22.7%	20.8%
Outer regional	22.5%	10.3%
Remote	8.9%	1.8%
Very remote	14.2%	1.1%
All of Australia	100% 194,249 children	100% 4,050,445 children

Data from: AIHW 2009: A Picture of Australia's Children 2009 (614)

For the decade 1996 to 2006, the proportion of the Australian population that was aged 0–14 years increased progressively with increasing remoteness from major cities (613, 615). This may be partly due to the younger age distribution of indigenous people and the known higher fertility rate of people in rural and remote areas (613). Table 23 shows that absolute numbers of children declined between 2001 and 2006 in all areas of Australia outside the major cities, while numbers in the major cities and the total number of children in Australia increased.

TABLE 24 CHANGE IN NUMBER OF CHILDREN AGED 0–14 YEARS IN AUSTRALIA BY REMOTENESS AREA. IN BRACKETS: % OF ALL AUSTRALIAN CHILDREN

	Major city	Inner regional	Outer regional	Remote	Very remote	Total
2001	2,520,842 (63%)	883,436 (22%)	453,253 (11%)	80,083 (2%)	49,585 (1%)	3,987,198 (100%)
2006	2,671,308 (66%)	842,709 (21%)	415,956 (10%)	74,765 (2%)	44,850 (1%)	4,050,445 (100%)

Data from AIHW (2005) Rural, Regional and Remote Health: Indicators of Health (616); AIHW (2008) Rural, Regional and Remote Health: Indicators of Health System Performance (617)

Appendix 4: History of government involvement in healthcare in Australia

From the arrival of the first fleet in 1788 until 1848, medical services in the colony of NSW were controlled, supervised and financed by the Colonial Administration (618, 619). Four of the nine naval surgeons who arrived at Sydney Cove with the first fleet were given (by the British Colonial Office) the task of establishing a Colonial Medical Service in the colony. This was to involve the establishment of hospitals in Sydney and in satellite towns as they developed, and the provision of medical care to convicts, military personnel and civil staff (618). Quite early in the history of the colony (in 1808), the Colonial Administration required specific medical qualifications to be listed before it granted permission to practice (618).

From the first European settlement in 1788, until 1836, medical services in the Colony and its various outposts (including Van Diemen's Land) were based in the Convict Hospitals which were constructed by order of successive Governors, and manned by surgeons and lay assistants, appointed by order the Governor under powers granted by the Colonial Under Secretary in London, and financed by the British Treasury (304, 618). The first hospital in the new colony was a tent on the shore of Sydney Cove. This was succeeded by a more permanent brick structure and by other similar hospitals in outposts of the colony at Parramatta, Liverpool, Windsor, Port Macquarie, Newcastle and Van Diemen's Land, as the settlements spread (304).

Anyone in the colony who depended on the Government for services or assistance was treated gratis in the Convict Hospitals. Soldiers and naval personnel were also treated without charge in either a military or a convict hospital. Members of the civil service, emancipants and free settlers were treated in their own homes by colonial surgeons, equipment and such medicines as were needed, being provided free by the hospitals (618). After a Board of Inquiry in 1839, a sliding scale of fees for medical services was introduced, the lowest fees being for assigned (convict) servants and the highest for free settlers.

From 1836 until 1848, as the transportation of convicts to NSW declined (eventually ceasing in 1841). Control of convict hospitals and their attendant surgeons (and hence, effectively, of all medical services in the colony) was taken over by the Army, ostensibly to improve the financial scrutiny of the hospitals and the flow of medical equipment and supplies from central stores in Sydney to outlying hospitals and district settlements (618).

Friendly societies

In the first decades after the foundation of the colony, age, chronic illness and disability, emancipation of convicts and the immigration of settlers without means of obtaining an income, left an increasing group of "indigent poor" (618). To offer relief to these, the Benevolent Society was formed in 1818, financed by subscription and by public appeals (304, 618, 620).

This organization built the Sydney Asylum to provide shelter for its pensioners, including the chronically ill and disabled, because the Sydney Infirmary (successor to the original Rum Hospital and predecessor of Sydney Hospital) was only willing to accept those with acute curable illnesses or injuries (618). Other such asylums were founded in the subsequent decades in outlying settlements such as Liverpool and Port Macquarie, and usually in the buildings of former Convict Hospitals (618, 619). Despite being taken over by the Colonial Government in 1862, these asylums, the predecessors of today's public hospitals, were notable mainly for maladministration and their poor care of inmates, at least until the 1890s (618).

In the absence of a system to provide healthcare to the entire population, the friendly societies flourished in Australia, especially in NSW and Victoria. Even in the 1940s, 25% of the Australian population received healthcare provided by mutual assistance societies. These bodies employed medical practitioners on contract to provide a level of care to their subscribers that became increasingly inadequate after World War II, as advances in medical knowledge and techniques made medical care more complex (621).

Rural hospitals

As rural settlements expanded in the early 19th century, local hospitals were built mainly by subscription from local residents (usually with a grant of land by the government) and staffed by surgeons of varying degrees of experience, training and competence, while some care was provided by private doctors and apothecaries in patients' own homes. Local doctors provided honorary care to the poor. Half of the running costs of the hospitals was provided by the government, and the remainder from local subscription. This limited the hospitals' capabilities and the level of care provided, especially in hospitals in smaller and less affluent areas (622).

Voluntary hospitals

These hospitals commenced operation with the foundation of the Sydney Dispensary as a private charity in 1826. Initially, subscribing doctors bought the right to treat private patients at the hospital, according to the amount of the doctor's subscription, while treating poorer patients gratis, on an

honorary basis. This “honorary” system of provision of care of public patients persisted until the late 1970s.

By 1845, the Government of the Colony had begun supporting the voluntary hospitals, and was providing 50% of the finance for their maintenance (618). Until the Second (NSW) Royal Commission on Public Charities in 1888–89, the hospitals and their boards were essentially autonomous, with little government control or oversight of their financial management or of the quality of medical care which they provided (618, 622).

The first public hospital in Melbourne was established in a cottage in the new village, shortly after the proclamation of the Port Phillip District of New South Wales in 1836, then in a two-storied building, and finally in 1845, a 20-bed hospital (the Melbourne Hospital) was built with the aid of a Government grant of land and of £1000, as well as by private subscription (623). In this way, the Government of the Victorian Colony (made independent of New South Wales in 1851) was involved in the establishment and management of hospital-based health care almost from the outset, providing most of the funding for the (public) charity hospitals, though initially, Governor Gipps regarded the provision of a general hospital for Melbourne as being the role of private charity rather than a duty of government (619). The pattern of predominantly government funding of voluntary hospitals was also seen in the settlements of Brisbane, Adelaide and Tasmania (619).

In both NSW and Victoria, there was considerable resistance (lasting until the late 20th century) from private doctors who provided honorary services to the public hospitals to the increasing influence of state governments in the administration of the hospitals. It was feared that government involvement and the appointment of full-time staff doctors would lead to socialised medicine and loss of independence of private doctors (624).

Medical administration

Until 1881 in NSW there was no Government Medical Service per se (618). In the 10 years before and after the Colony became self-governing (in 1855), government medical services (which catered for the needs of convicts, the military and paupers) declined and eventually disappeared (with the exception of lunacy services) after transportation of convicts ceased in 1841. Hospitals were run by boards of governors, but between 1875 and 1900 in NSW, the government assumed an increasing role in providing medical care, building and funding hospitals and regulating their financial and clinical operations, and supervising the qualifications of their medical staff. Government nominees were placed on the governing boards of the larger public hospitals (622).

Thus, despite the resistance of some politicians in NSW, publicly funded medical care, including hospital care, came to be regarded by 1900, less as a charity available to the poor and the chronically ill, and more as a community service to which all were entitled (622). Medical training and certification however, remained outside government control. The medical school at Sydney University was founded in 1883 by means of a charitable bequest (625), and postgraduate qualifications in medicine and surgery remained in the control of the Royal Colleges in London, Edinburgh and Dublin.

Public Health

The colonial administration gradually involved itself in improving public health arrangements. Governors of the NSW colony in the 1820s and 30s began to regulate sale of alcoholic liquors, to control the marketing of food, the burial of the dead and to insist on standards of bread manufacture (620). Arrangements for quarantine were made in 1828 (626), and the NSW Quarantine Act was passed in 1832 following an outbreak of cholera in Europe. A sewerage system for Sydney was designed in 1835, but an effective system was not in place until 1857 (627).

Public health conditions in the colony of Port Phillip deteriorated over the 20 years after it was gazetted as a settlement, especially after the discovery of gold in Victoria, as Melbourne's population increased from 23,000 in 1851 to 140,000 in 1861. Without a drainage system or a secure clean water supply, adequate building regulations or public health education, typhoid, tuberculosis, syphilis and other diseases spread in the colony. In response to pressure from citizens and from doctors, a Public Health Authority was established in 1854, enabled by an Act of Parliament to promote public health in populous places (628).

The first Victorian Public Health Act was enacted in 1854, with further Acts appearing in 1883 and 1889, following smallpox epidemics in the colonies in the 1880s. Public Health Acts were produced in the other Australian colonies in subsequent years, the last being NSW in 1896 (620).

1901 until the present

In the first decade after Federation, the supply of healthcare services remained the responsibility of the States, the Commonwealth being only responsible for quarantine (629). The general position in the States continued to be one of voluntary hospitals with heavy Government support catering for the medical needs of the less well off, with private doctors caring for wealthier patients in their homes and private hospitals, and providing care on an honorary basis to public patients in the voluntary hospitals.

The prevailing attitude in the population emphasised the virtues of independence and personal responsibility (including for health care) (630). However, floods and drought in rural areas and episodes of severe financial instability, such as the depressions of the 1840s and 1890s, and the unreliability of gold prospecting as a source of income for the many new arrivals, meant that a considerable proportion of the population was dependent on government-supported healthcare (304).

The rapid improvements in medical knowledge, technology and treatments which began after the First World War, and the publicity given to them, brought the expectation that these improvements should be available to all (304), including public patients in government-supported hospitals. Demand for public hospitals increased in the 1920s and 30s, driven by improvements in clinician training and in equipment, and by the impoverishment of the middle class during the 1930s Depression (629).

A compulsory national health insurance scheme was planned in 1928 and again in 1938 and 1946, but was not implemented due to resistance from employers, the friendly societies and the medical profession (304, 630). The Federal Government introduced a voluntary national insurance scheme in 1950 (629). A pharmaceutical benefits scheme, first introduced in 1944 but found by the High Court to be unconstitutional, was reintroduced in 1946.

Universal health insurance began with Medibank in 1975. In the Medibank agreement, the Commonwealth paid the states 50% of the operating costs of public hospitals, and hospital services became available to all citizens without charge or means test (178). Medibank was partly dismantled and replaced with a voluntary insurance scheme over the next six years, but universal health insurance, known as Medicare, was reintroduced by the Hawke federal government in 1984. Under this scheme (largely funded by a 1% levy on personal income), payments are made from the Commonwealth to the states to compensate for fees foregone when patients choose to be public patients. Further funds are available to the states under Medicare for community health and for subsidies to private hospitals (304).

From the introduction of Medicare in 1984 until 2011, the Commonwealth made an Australian Health Care Agreement (or Medicare Agreement) with the states every five years. Under these agreements, the Commonwealth transferred funds to the states and territories which were responsible for providing free public hospital inpatient and outpatient services to all Australian citizens. These services were to include “timely” elective and emergency surgery and all medications needed by inpatients (631).

Following the COAG (Council of Australian Governments) meeting in 2011, the manner of distribution of funds was revised in an attempt to reduce cost shifting between levels of government. Under the revised agreement, the Commonwealth provides up to 50% of the funding of public hospitals, the remainder being provided by the states (631). Funds are allocated from a National Health Funding Pool and from state-managed funds to Local Hospital Networks, each of which administers one or more hospitals within a state (632). These allocations will be made according to service agreements between the states and the Local Hospital Networks. The States remain the system managers of the public hospital system and the Commonwealth has lead responsibility for GP and primary health care (632). The COAG 2012 agreement also assigns responsibility for aged care, disability care, veterans' healthcare services and healthcare for Indigenous Australians (632).

Increasing role of the Commonwealth in healthcare provision

The Commonwealth Department of Health was formed in 1921 in response to the epidemic of Spanish Influenza in 1918–19. Its role was limited to quarantine, public health education (notably in the area of venereal disease), vaccine production, the maintenance of public health laboratories and the prevention of disease (304).

The obligation of the Commonwealth to provide healthcare for ex-servicemen and women and their dependents required considerable investment in infrastructure (Repatriation Hospitals) and staff. With the passage of time since World War II, the need for specific veterans' infrastructure has declined.

The 1967 referendum expanded the powers of the Commonwealth, including those affecting healthcare. In particular, the Commonwealth was enabled to make specific provisions for Indigenous healthcare, and, starting in 1971, to establish Aboriginal medical services, of which by 2004 there were 140 throughout Australia (629).

Since 1984, Commonwealth and state governments have increasingly engaged in preventive health campaigns on smoking, road safety, work-related injuries, obesity, excessive alcohol consumption and immunisation. They have also undertaken measures such as increasing the tobacco and alcohol taxes and adjusting funding to make vaccines more readily available in all states.

Mental health and accommodation of the mentally ill has been a state responsibility since 1788, but Commonwealth funding first became available in 1992 to permit state mental health reforms. From the mid-1990s, this support allowed the closure of the large psychiatric institutions and transfer of their clients into the community (629).

In the 1990s, both the states and Commonwealth acted to improve the effectiveness of GPs. Divisions of General Practice were formed in 1992 to improve training and peer support for GPs, and facilitate coordinated care within general practices (633). Separate programs, both state and federal, aimed to improve multidisciplinary care of patients by improving the coordination of services (634).

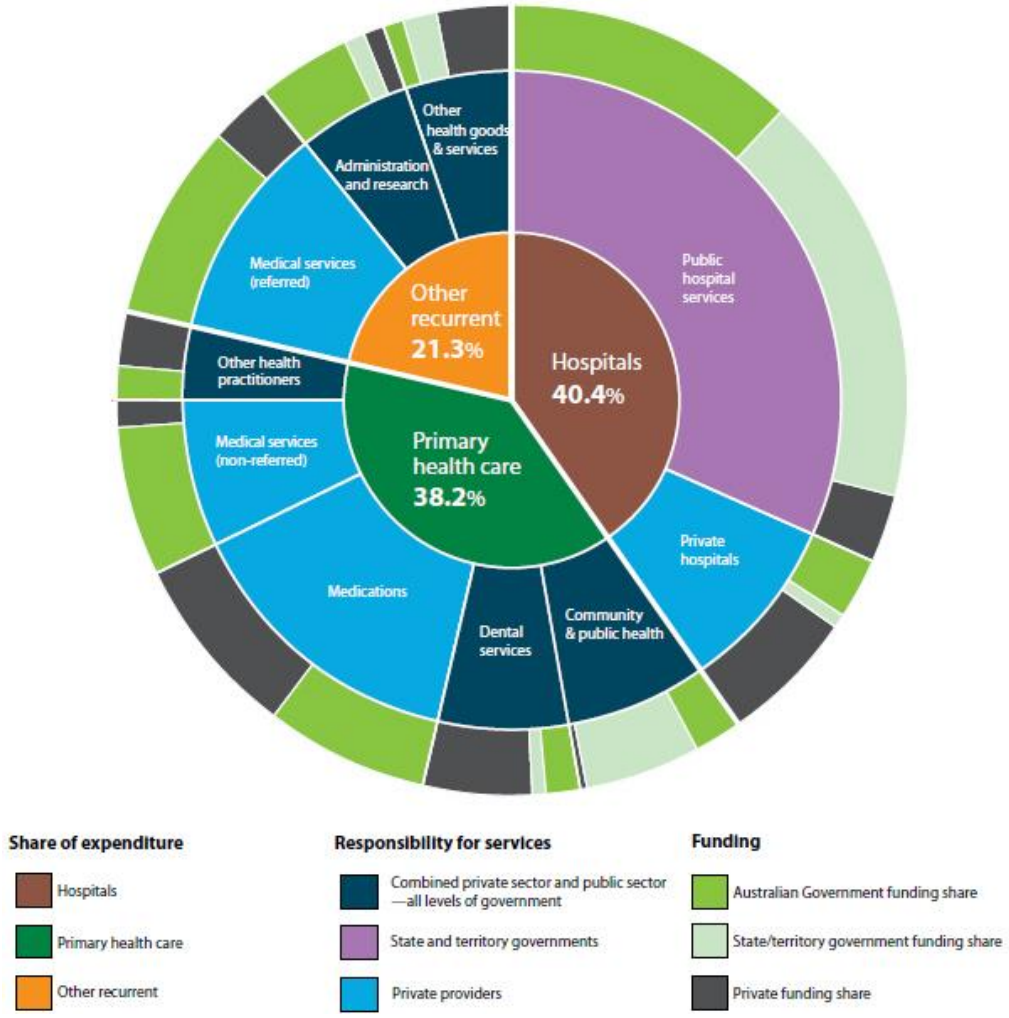
Organisation of healthcare service delivery in Australia in 2015

What has evolved from this complicated history is a health system funded by public (state or federal government) or private sources, delivered by government employees or private providers, and administered by private providers or by one of three levels of government (federal, state or local) (see section 2.5). Figure 17, from *Australia's Health 2014* (635), shows the allocation of total expenditure to broad categories of health service (innermost ring); detailed categories of service, with the body responsible for their delivery (middle ring) and for their funding (outer ring).

Figure 17 demonstrates the dissociation between responsible entity and funding source in the various healthcare modalities in Australia. For example, state governments are responsible for administration of public hospitals, whereas their funding is supplied by Commonwealth and state governments and from private funds. The same sources fund privately administered hospitals, but the proportions derived from each are different from those from public hospital funders.

As Figure 17 (middle ring) shows, many modalities of healthcare in Australia are provided and administered by a mixture of private sector and public sector providers and entities, where the public sector entities may be part of Commonwealth, state or local government. The geographic distribution of services for which government is responsible, and their allocation to particular patient groups, is directly affected by government RA decisions. Government policies and RA decisions can also indirectly affect the geographic distribution of services provided wholly or in part by private providers. For example, government incentives for clinicians to work in more remote areas, and the conditions placed on medical provider numbers, can have a marked effect on the composition of the medical, nursing and allied health workforce in rural areas (many of whom are private providers) and hence on the services available to the rural population (636).

FIGURE 18 RESPONSIBILITY FOR FUNDING AND DELIVERY OF HEALTH SERVICES IN AUSTRALIA



Adapted from AIHW (2014) *Australia's Health 2014* (635)

Appendix 5: Search terms used in the database search

Medline

The thesaurus search of Medline used the terms:

a. [(health priorities/economics, ethics, organization) OR (health policy/) OR (health services accessibility/)]
b. [(rural population/) OR (rural health/) OR (exp rural health services/) OR (hospitals, rural/) OR (medically underserved area/)]
c. [(resource allocation/) OR (health care rationing/) OR (financing, government/) OR ("delivery of health care"/economics, ethics, organization) OR (exp "costs and cost analysis"/) OR (exp nursing services/ economics, ethics, organization) OR (health facility planning/) OR (hospital planning/) OR (health systems plans/) OR (regional medical programs/) OR(state health plans/)

A search of a AND b AND c, limited to English language AND child 0-18 years (allocation of healthcare resources to rural children), yielded 391 references. When articles which referred only to the US, continental Europe or developing countries were excluded (**sieve 1**), 72 remained. The titles and abstracts of these articles were examined, and only articles which discussed the process of resource allocation were retained (**sieve 2**),20 remained.

The text of these articles was examined, and only those relevant to the topic (7 references) were retained.

Cinahl

A thesaurus search of Cinahl database, using the terms:

[(rural health) OR (rural health centers) OR (hospitals, rural) OR (services for Australian rural or remote allied health) OR (rural health services) OR (rural health nursing) OR (rural population)] AND [(health services needs and demand) OR (health services accessibility) OR (indigenous health) OR (health facility administrators) OR (health facility planning (ethics or economics)) OR (health facility closure) OR (health care delivery) OR (health resource allocation) OR (health policy (economics or management)) OR (decision making, organizational or resource allocation)] AND [(ethics, organizational) OR ethics OR (ethics, medical (organizational)) OR (decision making, ethical)

yielded 6 references. When the term AND [child OR (child health)] was added, no references remained.

Embase

A thesaurus search of Embase, using the terms:

[(health care availability) OR (health care planning) OR (health care) OR (health service) OR (health care access) OR (health care policy) OR (health care organization) OR (health care facilities and services) OR (resource management) OR (health care distribution) OR (health care facility)] AND [(cost or economic aspect) OR (health care cost) OR (cost benefit analysis) OR (resource allocation) OR (resource management) OR (decision making) OR (ethical decision making) OR (medical decision making) OR organization OR (organization and management) AND [(rural area) OR (rural health care) OR (rural health nursing) OR (rural population)]

yielded 307 references. When the term AND child was added, 2 references remained, neither of which was relevant to this search.

EBSCO

A thesaurus search of EBSCO Academic Search Complete (database) using the terms:

[(political ethics) OR (decision making, moral and ethical aspects) OR (right to health care) OR (health services accessibility) OR (child health services)] AND [(medical care) OR (health services administration) OR (health services administrators) OR (health facilities) OR (health planning) OR (medical policy) OR (health care rationing) OR (medical policy) OR (health programs) OR (child health services)] AND [(rural geography) OR (rural children) OR (rural health clinics) OR (rural families) OR (rural health) OR (rural health services) OR (rural hospitals) OR (rural medicine) OR rurality]

yielded one reference, which was not relevant to this search.

The same search, repeated in EBSCO Health Business Elite and Health Source, nursing/academic edition, yielded 46 references. On inspection of the titles and abstracts of these, no new, relevant references were found.

Pubmed

A PubMed search using the terms:

Health* AND ethic* AND [allocation OR (allocation of resources) OR (resource allocation)] AND child*

yielded 444 references. Application of sieve 1 (see above) yielded 5 references. On examination of the text of these articles, none discussed the process of decision-making in practice.

Search of smaller databases

The following search strategy was used to search all fields of a number of databases which appeared likely to contain references relevant to this topic:

[ethic* OR ethical principles] AND [health* OR health care] AND [resource* OR resource allocation OR allocation of resources] AND [rural* OR remote OR remote area] AND [child* OR child health]

The databases searched using this strategy:

APAIS Health; AGIS plus text; AGIS-ATSIS; AIATSIS; Families and Society Collection; Australasian Medical Index 1968-2009; ATSI Health; APAIS-ATSIS; Family; Health and Society; Health Collection; Humanities and Social Sciences Collection; Rural and Remote Health Database; Theses (NUS theses collection 1947-2007; APA-FT (These databases, with predominantly Australian content, are all administered by Informit); Web of Science Core Collection; Web of Science CABI (CAB abstracts and Global Health) administered by Web of Science; Political Science Complete (EBSCO); Worldwide Political Science Abstracts; ABI Inform Complete (ProQuest); JSTOR; Google Scholar.

Appendix 6: Journals, of which the Jan 1990 – Dec 2014 lists of contents were searched

- American Journal of Bioethics
- Australian and New Zealand Journal of Public Health
- Australian Health Review
- Australian Journal of Rural Health
- Chisholm Health Ethics Bulletin
- Cost Effectiveness and Resource Allocation
- Hastings Center Report
- Health and Place
- Health Care Analysis
- Healthcare Papers
- Health Policy
- Health Policy and Planning
- Journal of Health Economics
- Journal of Law and Medicine
- Journal of Medical Philosophy
- Journal of Primary Health
- Milbank Memorial Fund Quarterly
- Monash Bioethics Review
- Philosophy and Public Affairs
- Rural and Remote Health

Appendix 7: Criteria used in critical assessment tools for each category of paper

Category of paper appraised	Source of appraisal tool	Appraisal questions
Case study Alexander1998(312), Hyde 2007(296)	CEBMa	Did the study address a clearly focused question?
		Is the study design appropriate to answer the research question?
		Are the setting and the subjects representative?
		Is the researcher's perspective clearly described and taken into account?
		Are the data collection methods clearly described?
		Are the data analysis methods valid and reliable?
		Was the analysis repeated by more than one researcher?
		Are the results credible and relevant to practice?
		Are the conclusions justified by the results?
		Are the findings transferable to other settings?
Survey Baghbanian2011(235), McKie2011(335), Nord 1995a(313), Ross1995(236)	CEBMa	Did the study address a clearly focused question?
		Is the study design appropriate to answer the research question?
		Is the method of selection of subjects clearly described?
		Could the sampling method introduce selection bias?
		Was the sample representative of the population of interest?
		Was the sample size based on pre-study estimate of statistical power?
		Was a satisfactory response rate achieved?
		Are the questionnaires likely to be valid and reliable?
		Was the statistical significance assessed?
		Are confidence intervals given for the main results?
		Could there be confounding factors that have not been accounted for?

		Can the results be applied to your area of study?
Qualitative research Kirigia(265), Baghbanian2012(283), Gallego2009a&b(216, 310), Nord1995b(311)	JBI	Is the research methodology congruent with the philosophical perspective?
		Is the research methodology congruent with the research question?
		Is the research methodology congruent with the data collection methods?
		Is the research methodology congruent with the data analysis?
		Is the research methodology congruent with the interpretation of results?
		Is the researcher's cultural or theoretical position stated?
		Is the researcher's influence on the research and vice versa discussed?
		Are the participants and their voices adequately represented?
		Is the research ethical by current criteria and is there Ethics approval?
		Do the conclusions follow from the analysis and interpretation of the data?
Text and opinion Lin(302), Lewis(303), Keren(309), Ham and Coulter(162), Hicks1985(266)	JBI	Is the source of the opinion clearly identified?
		Does the source of opinion have standing in the field?
		Are the interests of the relevant population the central focus of the opinion?
		Is the opinion the result of a logical analytical process?
		Is there reference to the extant literature?
		Is any incongruence with the literature logically defended?
Systematic reviews Guindo(264), Galani(308)	JBI	Is the review question clearly and explicitly stated?

		Were the inclusion criteria appropriate for the review question?
		Was the search strategy appropriate?
		Were the sources and search resources adequate?
		Were the criteria for appraising studies appropriate?
		Was critical appraisal conducted by 2 or more independent reviewers?
		Were there methods to minimise errors in data extraction?
		Were the methods to combine studies adequate?
		Was the likelihood of publication bias assessed?
		Were the recommendations for policy or practice supported by the data?
		Were the specific directions for new research appropriate?

CEBMa is The Center for Evidence-based Management (637); JBI is the Joanna Briggs Institute(JBI) (638)

Appendix 8: University of Melbourne Human Research Ethics Committee Approval Letter for a Standard Project

themisPROD-noreply@unimelb.edu.au Mar 2

Dear Dr Palmer

I am pleased to advise that the Health Sciences Human Ethics Sub-Committee has approved the following Project:

Project Title: The ethics of allocating healthcare resources to rural children
Researchers: R Henning, Dr V J Palmer, Prof M J Temple-Smith
Ethics ID: 1647542

The Project has been approved for the period: 02-Mar-2017 to 31-Dec-2017

A signed letter confirming this approval will be forwarded to you shortly.

It is your responsibility to ensure that all people associated with the Project are made aware of what has actually been approved.

Research projects are normally approved to 31 December of the year of approval. Projects may be renewed yearly for up to a total of five years upon receipt of a satisfactory annual report. If a project is to continue beyond five years a new application will normally need to be submitted.

Please note that the following conditions apply to your approval. Failure to abide by these conditions may result in suspension or discontinuation of approval and/or disciplinary action.

(a) Limit of Approval: Approval is limited strictly to the research as submitted in your Project application.

(b) Variation to Project: Any subsequent variations or modifications you might wish to make to the Project must be notified formally to the Human Ethics Sub-Committee for further consideration and approval. If the Sub-Committee considers that the proposed changes are significant, you may be required to submit a new application for approval of the revised Project.

(c) Incidents or adverse effects: Researchers must report immediately to the Sub-Committee anything which might affect the ethical acceptance of the protocol including adverse effects on participants or unforeseen events that might affect continued ethical acceptability of the Project. Failure to do so may result in suspension or cancellation of approval.

(d) Monitoring: All projects are subject to monitoring at any time by the Human Research

Ethics Committee.

(e) Annual Report: Please be aware that the Human Research Ethics Committee requires that researchers submit an annual report on each of their projects at the end of the year, or at the conclusion of a project if it continues for less than this time. Failure to submit an annual report will mean that ethics approval will lapse.

(f) Auditing: All projects may be subject to audit by members of the Sub-Committee.

If you have any queries on these matters, or require additional information, please contact me using the details below.

Please quote the ethics ID number and the title of the Project in any future correspondence.

On behalf of the Sub-Committee I wish you well in your research.

Ms Hilary Young
Secretary, Health Sciences HESC
Phone: 03 8344 8595, Email: hilary.young@unimelb.edu.au

Appendix 9: Child Population Health Survey 2012 Questionnaire

Contents

Question Code	Question Name	2012 Notes	Age Groups	Question
HSU2aH	Type of hospital for most recent overnight stay		All	**Can you tell me if the overnight stay was at a public or private hospital?** 1 Public Hospital 2 Private Hospital 3 Private Hospital attached to a Public Hospital X Don't know R Refused
HSU6H	Rating of care for most recent overnight hospital stay		All	If HSUS1a= Hospital **Overall, what do you think of the care you /[child] received at the last hospital you attended? Was it…?** [READ OUT] **1 Excellent** **2 Very Good** **3 Good** **4 Fair** **5 Poor** X Don't know R Refused
HSU7H	Reason for rating most recent overnight hospital stay as fair/poor		All	If HSU6H =FAIR/POOR **Could you briefly describe why you rated the care you /[child] received as fair/poor?** [Open-Ended]
HSU6ED	Rating of care for most recent emergency department visit		All	If HSUS1a= Emergency Department **Overall, what do you think of the care you / [child] received at the emergency department you last attended? Was it…?** [READ OUT] **1 Excellent** **2 Very Good** **3 Good** **4 Fair** **5 Poor** X Don't Know R Refused
HSU7ED	Reason for rating most recent emergency department visit as fair/poor		All	If HSU6ED=FAIR/POOR **Could you briefly describe why you rated the care you/[child] received as fair / poor?** [Open-Ended]

Question Code	Question Name	2012 Notes	Age Groups	Question
HSU4	Currently visiting early childhood centre		Children 0-4 years	**Is [child] seeing a baby health or early childhood health nurse on a regular basis?** (PROMPT: includes regular visits to early childhood health centre or baby health centre) (PROMPT: regular visits means attended last appointment and plan to take child again) 1. Yes → HSU6B 2. No X Don't know → HSU6B R Refused → HSU6B
HSU5	Reason for not currently visiting early childhood centre		Children 0-4 years	**Can you tell me the main reason [child] is not seeing a baby health or early childhood health nurse?** 1 Centre at inconvenient location 2 Centre has inconvenient/unsuitable hours 3 Insufficient services 4 Unwelcome atmosphere 5 No need to attend / any more 6 Not useful / Not useful any more 7 Use other services instead 8 Other [SPECIFY]_____ 9 Next scheduled visit not due yet 88888 Don't Know 99999 Refused
HSU6B	Rating of overall care at early childhood centre		Children 0-4 years	If HSUS1a= Early childhood centre **Overall, what do you think of the care [child] received at the most recent early childhood centre visit? Was it…?** [READ OUT] **1 Excellent** **2 Very Good** **3 Good** **4 Fair** **5 Poor** X Don't Know R Refused
HSU7B	Reason for rating overall care at early childhood centre as fair/poor		Children 0-4 years	If HSU6B=FAIR/POOR **Could you briefly describe why you rated the care [child] received as fair / poor?** [Open-Ended]

Question Code	Question Name	2012 Notes	Age Groups	Question
HSU6CH	Rating of care for most recent community health centre visit			If HSUS1a= Community health **Overall, what do you think of the care you / [child] received at the Community health Centre you last attended? Was it…?** [READ OUT] **1 Excellent** **2 Very Good** **3 Good** **4 Fair** **5 Poor** X Don't Know R Refused
HSU7CH	Reason for rating most recent community health centre visit as fair/poor			If HSU6CH=FAIR/POOR **Could you briefly describe why you rated the care you/[child] received as fair / poor?** [Open-Ended]
HSU6PD	Rating of care for most recent public dental service visit		All	If HSUS1a= Public Dental **Overall, what do you think of the care you / [child] received at the most recent public dental service visit? Was it…?** [READ OUT] **1 Excellent** **2 Very Good** **3 Good** **4 Fair** **5 Poor** X Don't Know R Refused
HSU7PD	Reason for rating most recent public dental service visit as fair/poor		All	If HSU6PD=FAIR/POOR **Could you briefly describe why you rated the care you / [child] received as fair poor?** [Open-Ended]
HSU5GP	Last see a GP		All	If HSUS1a= General Practitioner **When did you last see a general practitioner?** 1 Within the last week 2 1 to 2 weeks ago 3 2 weeks to 1 months ago 4 between 1 and 6 months 5 6 to 12 months ago X Don't Know R Refused

Question Code	Question Name	2012 Notes	Age Groups	Question
HSU6GP	Rating of care for most recent General Practitioner visit		All	**Overall, what do you think of the care you / [child] received at the most recent general practitioner visit? Was it…?** [READ OUT] **1 Excellent** **2 Very Good** **3 Good** **4 Fair** **5 Poor** X Don't Know R Refused
HSU7GP	Reason for rating most recent General Practitioner visit as fair/poor		All	If HSU6GP=FAIR/POOR **Could you briefly describe why you rated the care you / [child] received as fair poor?** Description:_____
HSU6S	Rating of care for most recent specialist visit		All	If HSUS1a= Specialist **Overall, what do you think of the care you / [child] received at the specialist you/(child) last attended? Was it…?** [READ OUT] **1 Excellent** **2 Very Good** **3 Good** **4 Fair** **5 Poor** X Don't Know R Refused
HSU7S	Reason for rating most recent specialist visit as fair/poor		All	If HSU6S=FAIR/POOR **Could you briefly describe why you rated the care you/[child] received as fair / poor?** [Open-Ended]
HSU12n	Home-visit in last 12 months		0-11 months	**In the last 12 months, has a child or community nurse visited [child] in your home?** 1 Yes 2 No X Don't Know R Refused

Question Code	Question Name	2012 Notes	Age Groups	Question
HSU6C	Rating of overall care from community nurse in last 12 months		0-11 months	IF HSU12n = 1 **Overall, what do you think of the care / [child] received from this child and community nurse?** [READ OUT] **1 Excellent** **2 Very Good** **3 Good** **4 Fair** **5 Poor** X Don't Know R Refused
HSU7C	Reason for rating overall care by community nurse as fair/poor		0-11 months	**Could you briefly describe why you rated the care you / [child] received as fair/poor?** Description:_____
HSU14	Difficulties in getting health care		All	**Do you have any difficulties getting health care when you need /[child] needs it?** 1 Yes 2 No → HSU16 3 Don't need health care → HSU16 X Don't Know → HSU16 R Refused →HSU16
HSU15	Types of difficulties in getting health care		All	**Please describe the difficulties you have.** [PROBE FULLY] Description:_____ →CHSZ
HSU16	Comments on health services in local area		All	**Do you have any comments on the health services in your local area?** [PROBE FULLY] Description:_____

Appendix 10: 2011–12 Child Population Health Survey Data Dictionary

HSU14	$1	$CHSU14F	Difficulties in getting health care	Do you have any difficulties getting health care when child needs it?	Single response	1. Yes 2. No 3. Don't need health care R. Refused X. Don't know
HSU15_1	$1	$C_MC_CD	Types of difficulties in getting health care : Waiting time for GP appointment	Please describe the difficulties you have.	Part of multiple response question	0. No 1. Yes
HSU15_2	$1	$C_MC_CD	Types of difficulties in getting health care : Difficulty getting after hours GP appointment	Please describe the difficulties you have.	Part of multiple response question	0. No 1. Yes
HSU15_3	$1	$C_MC_CD	Types of difficulties in getting health care : Shortage of GPs in area	Please describe the difficulties you have.	Part of multiple response question	0. No 1. Yes
HSU15_4	$1	$C_MC_CD	Types of difficulties in getting health care : No bulk billing	Please describe the difficulties you have.	Part of multiple response question	0. No 1. Yes
HSU15_5	$1	$C_MC_CD	Types of difficulties in getting health care : Difficulty in accessing specialists	Please describe the difficulties you have.	Part of multiple response question	0. No 1. Yes
HSU15_6	$1	$C_MC_CD	Types of difficulties in getting health care : Waiting time for dental services	Please describe the difficulties you have.	Part of multiple response question	0. No 1. Yes
HSU15_7	$1	$C_MC_CD	Types of difficulties in getting health care : Shortage of health services	Please describe the difficulties you have.	Part of multiple response question	0. No 1. Yes
HSU15_8	$1	$C_MC_CD	Types of difficulties in getting health care : Emergency department waiting time	Please describe the difficulties you have.	Part of multiple response question	0. No 1. Yes
HSU15_9	$1	$C_MC_CD	Types of difficulties in getting health care : Quality of treatment	Please describe the difficulties you have.	Part of multiple response question	0. No 1. Yes
HSU15_10	$1	$C_MC_CD	Types of difficulties in getting health care : Waiting time for elective surgery	Please describe the difficulties you have.	Part of multiple response question	0. No 1. Yes
HSU15_11	$1	$C_MC_CD	Types of difficulties in getting health care : Cost of health care services	Please describe the difficulties you have.	Part of multiple response question	0. No 1. Yes
HSU15_12	$1	$C_MC_CD	Types of difficulties in getting health care : Other transport issues	Please describe the difficulties you have.	Part of multiple response question	0. No 1. Yes
HSU15_13	$1	$C_MC_CD	Types of difficulties in getting health care : Other	Please describe the difficulties you have.	Part of multiple response question	0. No 1. Yes
HSU6B	$1	$CHSU6BF	Rating of overall care at early childhood centre	Overall, what do you think of the care child received at the most recent early childhood centre visit?	Single response [Read out]	1. Excellent 2. Very Good 3. Good 4. Fair 5. Poor R. Refused X. Don't know
HSU6C	$1	$CHSU6CF	Rating of overall care from community nurse in last 12 months	Overall, what do you think of the care child received from this child and community nurse?	Single response [Read out]	1. Excellent 2. Very Good 3. Good 4. Fair 5. Poor R. Refused X. Don't know
HSU6CH	$1	$CHS6CHF	Rating of care for most recent community health centre visit	Overall, what do you think of the care child received at the community health centre last attended? Was it...	Single response [Read out]	1. Excellent 2. Very Good 3. Good 4. Fair 5. Poor R. Refused X. Don't know
HSU6ED	$1	$CHS6EDF	Rating of care for most recent emergency department visit	Overall, what do you think of the care child received at the emergency department child last attended?	Single response [Read out]	1. Excellent 2. Very Good 3. Good 4. Fair 5. Poor R. Refused X. Don't know
HSU6GP	$1	$CHS6GPF	Rating of care for most recent GP visit	Overall, what do you think of the care child received at the most recent GP visit? Was it...	Single response [Read out]	1. Excellent 2. Very Good 3. Good 4. Fair 5. Poor R. Refused X. Don't know

HSU6H	$1	$CHSU6HF	Rating of care for most recent overnight hospital stay	Overall, what do you think of the care child received at the last hospital he/she attended? Was it...	Single response [Read out]	1. Excellent 2. Very Good 3. Good 4. Fair 5. Poor R. Refused X. Don't know
HSU6PD	$1	$CHS6PDF	Rating of care for most recent public dental service visit	Overall, what do you think of the care child received at the most recent public dental service visit? Was it...	Single response [Read out]	1. Excellent 2. Very Good 3. Good 4. Fair 5. Poor R. Refused X. Don't know
HSU6S	$1	$CHSU6SF	Rating of care for most recent specialist visit stay	Overall, what do you think of the care child received at the specialist he/she last attended? Was it...	Single response [Read out]	1. Excellent 2. Very Good 3. Good 4. Fair 5. Poor R. Refused X. Don't know
HSU7B_1	$1	$C_MC_CD	Reason for rating overall care at early childhood centre as fair/poor : Insufficient services offered/staff shortages	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7B_2	$1	$C_MC_CD	Reason for rating overall care at early childhood centre as fair/poor : Poor attitude of staff	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7B_3	$1	$C_MC_CD	Reason for rating overall care at early childhood centre as fair/poor : Poor technical skill of staff	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7B_4	$1	$C_MC_CD	Reason for rating overall care at early childhood centre as fair/poor : Waiting time	Could you briefly describe why you rated the care child received as fair/poor? Description:	Part of multiple response question	0. No 1. Yes
HSU7B_5	$1	$C_MC_CD	Reason for rating overall care at early childhood centre as fair/poor : Other	Could you briefly describe why you rated the care child received as fair/poor? Description:	Part of multiple response question	0. No 1. Yes
HSU7C_1	$1	$C_MC_CD	Reason for rating most recent community nurse as fair/poor : Poor attitude of nursing staff	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes

HSU7C_3	$1	$C_MC_CD	Reason for rating most recent community nurse as fair/poor : Other	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7CH_1	$1	$C_MC_CD	Reason for rating most community health centre visit as fair/poor : Insufficient services offered or staff shortages	Could you briefly describe why you rated the care child received as fair/poor? Description:	Part of multiple response question	0. No 1. Yes
HSU7CH_2	$1	$C_MC_CD	Reason for rating most community health centre visit as fair/poor : Poor attitude of staff	Could you briefly describe why you rated the care child received as fair/poor? Description:	Part of multiple response question	0. No 1. Yes
HSU7CH_3	$1	$C_MC_CD	Reason for rating most community health centre visit as fair/poor : Poor technical skill of staff	Could you briefly describe why you rated the care child received as fair/poor? Description:	Part of multiple response question	0. No 1. Yes
HSU7CH_4	$1	$C_MC_CD	Reason for rating most community health centre visit as fair/poor : Waiting time	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7CH_5	$1	$C_MC_CD	Reason for rating most community health centre visit as fair/poor : Contradictory diagnoses and/or diagnosis contradicted that of other clinicians (clinical/behavioural)	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7CH_6	$1	$C_MC_CD	Reason for rating most community health centre visit as fair/poor : Poor communication	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7CH_7	$1	$C_MC_CD	Reason for rating most community health centre visit as fair/poor : Cultural or sociological prejudices of staff	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7CH_9	$1	$C_MC_CD	Reason for rating most community health centre visit as fair/poor : Other	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7ED_1	$1	$C_MC_CD	Reason for rating most recent emergency department visit as fair/poor : Not enough staff	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes

HSU7ED_2	$1	$C_MC_CD	Reason for rating most recent emergency department visit as fair/poor : Poor accommodation quality	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7ED_3	$1	$C_MC_CD	Reason for rating most recent emergency department visit as fair/poor : Communication problems	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7ED_4	$1	$C_MC_CD	Reason for rating most recent emergency department visit as fair/poor : Poor attitude of clinical staff	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7ED_5	$1	$C_MC_CD	Reason for rating most recent emergency department visit as fair/poor : Poor technical skill of clinical staff	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7ED_6	$1	$C_MC_CD	Reason for rating most recent emergency department visit as fair/poor : Waiting time	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7ED_7	$1	$C_MC_CD	Reason for rating most recent emergency department visit as fair/poor : Sent home without treatment or follow-up	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7ED_8	$1	$C_MC_CD	Reason for rating most recent emergency department visit as fair/poor : Misdiagnosis or contradictory diagnoses	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7ED_9	$1	$C_MC_CD	Reason for rating most recent emergency department visit as fair/poor : Inadequate or wrong medication or management	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7ED_10	$1	$C_MC_CD	Reason for rating most recent emergency department visit as fair/poor : Poor service/unhappy with level of service	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7ED_11	$1	$C_MC_CD	Reason for rating most recent emergency	Could you briefly describe why you rated the care child received	Part of multiple response question	0. No 1. Yes

			department visit as fair/poor : Other	as fair/poor?		
HSU7ED_13	$1	$C_MC_CD	Reason for rating most recent emergency department visit as fair/poor : Refused	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7GP_1	$1	$C_MC_CD	Reason for rating most recent general practitioner visit as fair/poor : Can't find a GP I like (including GP has moved or retired)	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7GP_2	$1	$C_MC_CD	Reason for rating most recent general practitioner visit as fair/poor : Communication problems	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7GP_3	$1	$C_MC_CD	Reason for rating most recent general practitioner visit as fair/poor : Communication problems - lack of English on part of doctor	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7GP_4	$1	$C_MC_CD	Reason for rating most recent general practitioner visit as fair/poor : Inadequate or wrong medication or management (includes misdiagnosis or contradictory diagnosis/no answer to my problem/sent home without treatment or follow-up)	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7GP_5	$1	$C_MC_CD	Reason for rating most recent general practitioner visit as fair/poor : Lack of availability or other access problem	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7GP_6	$1	$C_MC_CD	Reason for rating most recent general practitioner visit as fair/poor : Lack of caring manner (include lack of interest, blasé, routine attitude/poor attitude of clinical staff)	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7GP_7	$1	$C_MC_CD	Reason for rating most recent general practitioner	Could you briefly describe why you rated the care child received	Part of multiple response question	0. No 1. Yes

			visit as fair/poor : Lack of technical skill of clinical staff	as fair/poor?		
HSU7GP_8	$1	$C_MC_CD	Reason for rating most recent general practitioner visit as fair/poor : Too expensive	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7GP_9	$1	$C_MC_CD	Reason for rating most recent general practitioner visit as fair/poor : Too far to go	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7GP_10	$1	$C_MC_CD	Reason for rating most recent general practitioner visit as fair/poor : Waiting time	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7GP_11	$1	$C_MC_CD	Reason for rating most recent general practitioner visit as fair/poor : Don't know	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7GP_13	$1	$C_MC_CD	Reason for rating most recent general practitioner visit as fair/poor : Unhappy with level of service	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7GP_14	$1	$C_MC_CD	Reason for rating most recent general practitioner visit as fair/poor : Other	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7H_1	$1	$C_MC_CD	Reason for rating most recent overnight hospital stay as fair/poor : Not enough staff	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7H_2	$1	$C_MC_CD	Reason for rating most recent overnight hospital stay as fair/poor : Poor quality accommodation	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7H_3	$1	$C_MC_CD	Reason for rating most recent overnight hospital stay as fair/poor : Communication problems	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7H_4	$1	$C_MC_CD	Reason for rating most recent overnight hospital stay as fair/poor : Poor attitude of clinical staff	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7H_5	$1	$C_MC_CD	Reason for rating most recent overnight hospital stay as fair/poor : Poor	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes

			technical skill of clinical staff			
HSU7H_6	$1	$C_MC_CD	Reason for rating most recent overnight hospital stay as fair/poor : Excessive time waiting for care	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7H_7	$1	$C_MC_CD	Reason for rating most recent overnight hospital stay as fair/poor : Poor or inadequate food	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7H_8	$1	$C_MC_CD	Reason for rating most recent overnight hospital stay as fair/poor : Inadequate or wrong medication or management	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7H_9	$1	$C_MC_CD	Reason for rating most recent overnight hospital stay as fair/poor : Surgery cancelled or sent home without treatment	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7H_10	$1	$C_MC_CD	Reason for rating most recent overnight hospital stay as fair/poor : Hospital could not offer required care	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7H_11	$1	$C_MC_CD	Reason for rating most recent overnight hospital stay as fair/poor : Poor service/unhappy with level of service	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7H_12	$1	$C_MC_CD	Reason for rating most recent overnight hospital stay as fair/poor : Other	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7PD_1	$1	$C_MC_CD	Reason for rating most recent public dental service visit as fair/poor : Insufficient services/staff shortage	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7PD_2	$1	$C_MC_CD	Reason for rating most recent public dental service visit as fair/poor : Poor attitude of staff	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7PD_3	$1	$C_MC_CD	Reason for rating most recent public dental service visit as fair/poor : Poor	Could you briefly describe why you rated the care child received as fair/poor? Description:	Part of multiple response question	0. No 1. Yes

			technical skill of staff			
HSU7PD_4	$1	$C_MC_CD	Reason for rating most recent public dental service visit as fair/poor : Waiting time	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7PD_5	$1	$C_MC_CD	Reason for rating most recent public dental service visit as fair/poor : Other	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7S_2	$1	$C_MC_CD	Reason for rating most recent specialist visit as fair/poor : Communication problems	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7S_4	$1	$C_MC_CD	Reason for rating most recent specialist visit as fair/poor : Inadequate or wrong medication or management (includes misdiagnosis or contradictory diagnosis/no answer to my problem)	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7S_5	$1	$C_MC_CD	Reason for rating most recent specialist visit as fair/poor : Lack of availability or other access problem	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7S_6	$1	$C_MC_CD	Reason for rating most recent specialist visit as fair/poor : Lack of caring manner (includes lack of interest, blasé, routine attitude, poor attitude of clinical staff)	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7S_7	$1	$C_MC_CD	Reason for rating most recent specialist visit as fair/poor : Lack of technical skill of clinical staff	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7S_8	$1	$C_MC_CD	Reason for rating most recent specialist visit as fair/poor : Too expensive	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7S_9	$1	$C_MC_CD	Reason for rating most recent specialist visit as fair/poor : Too far to go	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7S_10	$1	$C_MC_CD	Reason for rating most recent specialist visit as fair/poor : Waiting time	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7S_13	$1	$C_MC_CD	Reason for rating most recent specialist visit as fair/poor : Unhappy with level of service	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes
HSU7S_14	$1	$C_MC_CD	Reason for rating most recent specialist visit as fair/poor : Other	Could you briefly describe why you rated the care child received as fair/poor?	Part of multiple response question	0. No 1. Yes

Appendix 11: Interview guide for interviews with decision-makers and advisers

Please tell me about:

1. Administrative role: decision-making and/or advisory
2. To what groups (within Government and within the community) do you owe responsibility?
3. Responsibility for detail of programs and for coordination within Department and between Departments and levels of government
4. Characteristics of a good resource allocation decision (how do you tell whether a decision is a good one or not)
5. Obligations of a government to individuals in the population on whose behalf it governs
6. How should the needs of individuals, whose healthcare needs are much more expensive than the average, be treated?
7. Obligations of population as a whole, and its government, to give proportionately more consideration to the needs of rural people because we need them to live and work in areas that are remote from the resources that are available in the city
8. How should the needs of individuals or groups that are less powerful and less personally able than the average be treated
9. Treatment of children and their needs versus adults and their needs

Appendix 12: Approval letters from the University of Melbourne and Western NSW LHD Human Research Ethics Committees for interviews with officials

26 May 2016

Dr V.J. Palmer
General Practice
The University of Melbourne

Dear Dr Palmer

Project title: The ethics of allocating healthcare resources to rural children (interviews with government officials in NSW)

Researchers: Dr V J Palmer, Prof M J Temple-Smith, R Henning

Ethics ID: 1442237

I am pleased to advise that the amendment to this Project was approved by the General Practice Human Ethics Advisory Group on May 25, 2016.

Please note it is your responsibility to ensure that all people associated with the Project are made aware of the amendment.

Yours sincerely

A/Prof John Furler
Chair General Practice - Human Ethics Advisory GroupDepartment of General Practice

Melbourne Medical School
The University of Melbourne, 200 Berkeley Street Carlton Victoria 3053, Australia
T: + 61 3 8344 7276 F: + 61 3 9347 6136 E: gp-enquiries@unimelb.edu.au W: www.gp.unimelb.edu.au

26th July 2016

Health
Western NSW
Local Health District

Dr Robert Henning
Department of General Practice
University of Melbourne

Dear Dr Henning,

Greater Western Human Research Ethics Committee (HREC)
Project No. LNR/16/GWAHS/102

The ethics of allocating healthcare resources to rural children

Application for Ethical Review

The Greater Western HREC has been accredited by the NSW Ministry of Health as a lead committee to provide the single ethical and scientific review of proposals, to conduct research within the NSW public health system. Further, this committee is constituted and operates in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research and the CPMP/ICH Note for Guidance on Good Clinical Practice.

Your research project was reviewed by the HREC on the 21st July, 2016 and I am pleased to advise that ethical approval of this research project has been granted.

This HREC approval letter constitutes ethical approval only. You are required to submit a site specific assessment application for each site at which you wish to conduct this project. You must not commence this research project at a site until separate authorisation from the Chief Executive or delegate of that site has been obtained. A copy of this letter must be forwarded to all Principal Investigators at every site for submission to the relevant Research Governance Officer as part of the site specific assessment process.

The following documentation has been reviewed and approved by the HREC:

- LNR submission AU/6/CB4724 dated 6/7/2016
- Research Protocol Version No. 14 dated 6/7/2016
- Plain Language Statement for Senior Managers of the NSW Department of Health Version 6, dated 6/7/2016
- NSW Ministry of Health Privacy Questions sheet
- Curriculum Vitae – Robert Darien Henning
- Curriculum Vitae – Victoria Jane Palmer
- Curriculum Vitae – Meredith Temple-Smith
- University of Melbourne Human Ethics Advisory Group amendment approval letter dated 26 May 2016

- University of Melbourne Reviewer Feedback Sheet Ethics ID number 1442237.2 Ethical Review Checklist

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Greater Western Human Research Ethics Committee
Incorporating the Western NSW & Far West Local Health Districts

PO Box 143, Level 1, 230 Howick Street, BATHURST NSW 2795
Tel: (02) 6330 5941 Fax: (02) 6332 3140

The project is approved to be conducted at the following NSW Public Health sites:

- Far West Local Health District
- Western NSW Local Health District
- NSW Ministry of Health

Please note the following conditions of approval:

1. The coordinating investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including any unforeseen events that might affect continued ethical acceptability of the project.
2. Proposed changes to the research protocol, conduct of the research, or length of HREC approval will be provided to the HREC for review in the specified format.
3. The HREC will be notified, giving reasons, if the project is discontinued at a site before the expected date of completion.
4. The coordinating investigator will provide an annual report to the HREC and at completion of the study in the specified format.

HREC approval is valid for 5 years from the date of this letter.

Should you have any queries about your project please do not hesitate to contact the Greater Western HREC Executive Officer on (02) 6330 5889 or via email WNSWLHDEthicsCommittee@health.nsw.gov.au .

Please quote HREC Reference No. LNR/16/GWAHS/102 in all correspondence.

The HREC wishes you every success in your research.

Yours sincerely

David Turcato
Executive Officer
GW HREC

Appendix 13: The progressive concentration of services, including healthcare services, in major cities and regional centres

Growth of regional cities and larger towns

The decline in population of small Australian towns has been accompanied by moderate to strong growth in the population of larger towns and regional cities (639, 640). The pattern of internal population migration in Australia in the last hundred years has been movement of 18 to 21-year-olds from small towns and rural areas towards regional towns and capital cities in search of employment and education opportunities (640, 641). One effect of this is that the age profile of regional towns is much more even than that of small towns and rural areas, which contain a significantly lower proportion of 18 to 35-year-olds (the peak child-bearing years) than do cities and regional towns.

Although a smaller proportion of households in rural areas (other than towns) are single-parent households than in urban areas, a higher proportion of country town households are single-parent families, who have moved there from a city to find more affordable housing (642). These families are often recipients of government welfare benefits but find themselves at further disadvantage in smaller towns because of the lower level of public infrastructure there compared with that available in the cities (642). In 2001, while 17% of people in Major Cities were in the lowest 20% of the population ranked by gross household income, 27% of people in Outer Regional areas, 24% in inner Regional and 25% in Remote areas were in the lowest 20% (643).

Causes and effects of the decline of smaller Australian towns

The decline in farm incomes since the 1960s, together with increasing mechanisation and amalgamation of farms and the consequent emigration from small towns, has reduced the viability of retail and service businesses in those towns (644). This further reduced employment in the towns. Some small towns were founded in circumstances of workforce needs and economic environment which no longer exist, so that these towns have become redundant (645, 646).

With the loss of population, the justification for retaining public infrastructure such as schools, hospitals, police stations and free-standing post offices in a small town decreases. Thus, the number of teachers in a school is reduced by decision of the city-based education department, and the ability of the school to offer a wide range of subjects declines. This decreases the attractiveness of the school to local pupils: wealthier parents will be able to send their children to schools in the city or larger town, but poorer pupils will be left at the downgraded local school. Hospitals in smaller towns close beds or departments (such as the ED or the maternity unit), and in consequence lose ability to

attract GPs to the town. Each of these closures or partial closures of a piece of state infrastructure leads to further loss of employment, so the cycle of population loss and loss of services becomes self-perpetuating.

Consolidation of government services into larger centres is justified (by state and federal government departments) on the assumption that all of the population is mobile and has the means to travel by private or public transport when the need arises. As pointed out in sections 5.3 and 8.1, this is not always the case: not all families are mobile, so poorer, less mobile families will not have the same ability to reach government services when they are needed as more mobile families or as families in cities or large towns.

The role of government in the loss of services in small towns

Until the 1980s, the prevailing emphasis of Australian governments (both federal and state) in service provision to the rural population was on geographic equity. This included provision of services such as transport, health, education and communications, including post and telecommunications (639).

Since World War II, Keynesian policies, tacitly accepted by all three major political parties in Australia, had aimed to achieve some degree of spatial and temporal equity in the provision of services within Australia (644, 647). Provision of services such as health, education and transport, and the regulation, distribution and financing of those services, was seen as part of the proper function of government, although parallel private and semi-private systems for the provision of each service had long existed in Australia.

Since the early 1980s, major changes in the way state and federal governments operate, have combined with globalisation, technological change and deterioration in Australia's terms of trade in non-mining primary industry to lead to a contraction and "rationalisation" of those services which had previously been government functions (639). Economic rationalism, which now underpins many RA decisions by Australian governments, assumes that the market, freely functioning, will always produce better outcomes in terms of wealth creation, distribution and efficiency than government planning and regulation (648), and that economic goals have priority over social goods (647).

The "New Public Management" which emerged in the 1980s in Australia emphasised competition in between the public and private sectors in tendering for delivery of services; incentive-based remuneration, especially for managers; requirement for quantitatively measurable outcomes; emphasis on cost-cutting, staffing reduction and wage limitation; division of large government departments into smaller functional units, with decision-making close to the point of service

delivery; a somewhat flatter hierarchical structure; and active independent management by top (city-based) managers (649, 650). The requirement under this system for outcomes to be measurable and for the goals of departments and their corporatised subunits to be precisely defined (650), militates against any part of government taking a holistic view of the welfare of individuals or of their communities (651-653). This situation is exacerbated in Australia (and to a lesser extent in the post-devolution UK) by vertical inequalities in income and expenditure between central government (federal in Australia; UK in Britain), provincial governments (state in Australia; Scottish, Welsh and Northern Irish in Britain) and local government (654). While each level of government has its own independent sources of income, provincial and local governments are heavily dependent on funding allocations from the upper levels, and compete with others on the same level for those allocations. General-purpose funds from the Australian Federal Government decreased by 50% in real terms between 1985 and 2000 (651), putting severe pressure on state governments to reduce costs of all services including healthcare.

The combination of financial stringency and incentive-based remuneration has led managers of departments and their corporatised subunits to close or amalgamate services, including hospitals, EDs and some ambulatory services, especially in smaller towns, and to consolidate those services that remain into larger towns or regional cities. The reduction in direct service provision by government departments and their agencies in small towns has meant that more of those services are now contracted out to private entities based in larger towns or regional cities (655).

Even workers in government service-based industries who live in small towns have to commute to larger regional towns or cities to work. For example, the 2007 Department of Planning and Community Development study of small towns in Victoria concluded that the increase in population of workers in Stanhope in central Victoria who listed their occupation as health care must represent workers commuting to larger regional centres for work, since local employment at the Stanhope health centre had halved between 1988 and 2005 (656).

McKenzie (2000) described the effects of this contraction and consolidation of health services on families in the Western Australian wheat belt. In particular, she described a family who needed to make a 300-kilometre round trip for a medical consultation and pharmacy visit for a sick baby. She noted the difficulty, expense, inconvenience and distress engendered by lack of healthcare facilities in nearby towns, especially when a child and parent have to travel to a distant town or city for treatment, and especially when there are other children who must remain to be cared for at home (95).